DISORDERED EATING AND BODY DISSATISFACTION IN WOMEN WITH PHYSICAL DISABILITIES: A MIXED METHODS APPROACH

KALEY MAUREEN ROOSEN

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Abstract

Studies have shown that women with chronic illnesses/physical disabilities experience eating disorder symptoms at higher rates than those without. Limited research has explored the reasons behind disability as a potential risk factor for disordered eating/body dissatisfaction. The present study examined disordered eating and body dissatisfaction in young women with physical disabilities. The research used a mixed methods approach with a quantitative (Study 1) and a qualitative component (Study 2). Study 1 compared disordered eating, body dissatisfaction, and mental health problems in 114 women with physical disabilities with those without any disability. It further examined how reported disability severity related to disordered eating, body dissatisfaction and mental health symptoms. Results demonstrated that women with disabilities were more likely to experience higher anxiety and body dissatisfaction. In addition, poorer health rating was significantly associated with greater disordered eating and mental distress, while greater reported subjective disability was associated with greater body dissatisfaction. Study 2 used the grounded theory method to explore the experience of disordered eating in 11 women with physical disabilities from Study 1 who volunteered to be interviewed. Analyses informed by methodical hermeneutics supported the emergence of the core category: Surviving And Thriving In A World Not Designed For Disability And Difference, which captures the experience women with disabilities shared of coping with feelings and realities of being different. In terms of disordered eating, women experienced their eating as different and coped with their overall experience of being different using food, eating and other body modification strategies. The current research highlights the need for greater awareness and programming specified towards the unique needs of physically disabled women.

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Background

A recent case report of a 33-year-old with anorexia nervosa and cerebral palsy described a shocking case of a bright young woman pleading to die (Webb, Morgan, & Lacey, 2009). Her medical history presented as a confusing web of psychological and physical symptoms that left health care providers feeling desperate for treatment solutions. The case highlights the limited awareness of medical professionals regarding the comorbidity of physical disabilities and eating disorders, despite the fact that studies have suggested that women with chronic physical conditions are actually at increased risk for developing eating disorders and disordered eating symptoms (Bryon, Shearer, & Davies, 2008; Neumark-Sztainer, Story, Resnick, Garwick & Blum, 1995; Walkins, Sutton, & Lask, 2001). However, the etiological mechanisms related to comorbid eating disorders and physical disabilities remain poorly understood. Further, the presence of an eating disorder alongside an additional chronic medical condition exacerbates the level of stress and disability associated with either disorder, thereby, complicating treatment (Valli & Walkup, 1998). A greater understanding of the etiology, any manifestation differences, and treatment/support challenges in women with disabilities is needed and will aid in the improvement of eating disorder treatment and prevention programs.

In the following literature review, I explore previous research that links physical disability with disordered eating in addition to other associated risk factors. I begin with some introductory information about the population of women with physical disabilities and the biopsychosocial factors associated with their health and mental health. I then cover the existing research on disordered eating, obesity, body dissatisfaction, mental health and other quality of life challenges found to impact women with physical disabilities. Lastly, I conclude with a brief introduction to the different models conceptualizing disability in the current literature. Given

the paucity of research thus far examining disordered eating in women with physical disabilities, this paper highlights throughout specific challenges and obstacles that occur when researching and identifying disordered eating within this population.

Introduction to Physical Disability

In Canada, an estimated 17% of adult women are living with a disability (Belair & Statistics Canada, 2007). Further, 12% of those Canadian women reported that they had a significant mobility disability and the proportion of women reporting some form of activity limitation increases steadily with age (Statistics Canada, 2009). According to the World Health Organization's disability model, disability results from a complex interaction among a person's functional impairments (e.g., "problems in body function or structure such as a significant deviation or loss"), health conditions, and barriers within the physical and social environment (WHO, 2001). A physical disability, as defined in this dissertation, captures those women who experience impairments with their mobility and/or physical functioning. Members of the physically disabled community are diverse and can represent women with a congenital disorder that impacts their mobility/ability to walk (e.g., spina bifida, celebral palsy, muscular dystrophy), those with acquired injuries or conditions (e.g., multiple sclerosis, spinal cord injury), women with chronic illnesses or health conditions (e.g., fibromyalgia, arthritis), and/or those born with other bodily differences that impact their mobility in some way (e.g., amputation of limb(s), short-stature/dwarfism).

Women with physical disabilities have disproportionate prevalence rates of many health problems including, obesity, heath disease, osteoporosis, and other chronic conditions (Iezzoni, Wint, Smeltzer, & Ecker, 2001; Reichard & Fox, 2013; Weil et al., 2002). Further, people with disabilities report seeking more healthcare while simultaneously having greater unmet needs,

including vulnerability to secondary health conditions and other preventable diseases, higher rates of premature death, and increased likelihood of engaging in health risk behaviours (WHO, 2015). Socio-environmental barriers contribute to the fact that disabled women greatly under-utilize preventative healthcare services (Chevarley, Thierry, Gill, Ryerson, & Nosek, 2006). In addition, certain social disadvantages, including poverty, housing, unemployment, and discrimination, greatly contribute to other health inequities. For instance, according to the Canadian Community Health Survey (Statistics Canada, 2009), the average income of women with disabilities was about 70% that of women without activity limitations and was largely accounted for by high rates of unemployment in the disability community. Further, this income gap was much more pronounced for women than for men with disabilities, speaking to the intersection of disability and gender marginalization. Overall, women with disabilities were also more likely to report poor functional health (70% vs. 13%), mental health (47% vs. 24%), greater stress levels and lower general life satisfaction in comparison to those without disabilities (Crompton, 2011). Further, as will be explored in detail below, disabled women are disadvantaged in terms of healthy lifestyle behaviours, including access to healthy foods and physical activity (Fox, Witten, & Lullo, 2014). Despite this multifaceted and expansive list of increased health risk factors, women with disabilities remain an under-studied and under-researched population across numerous areas of study, health promotion/prevention projects, and funding bodies (WHO, 2015).

Disordered Eating and Physical Disability

Eating disorders (ED), including anorexia (AN) and bulimia nervosa (BN), binge eating disorder (BED) and eating disorder not otherwise specified (EDNOS), are a group of psychiatric diagnoses as defined by the Diagnostic and Statistical Manual (APA, 2013)

characterized by abnormal or disturbed eating habits that negatively impact a person's physical or mental health, typically motivated by a fear of weight gain or caused by other psychological factors (e.g., anxiety, extreme distress). Eating disorders have the highest mortality rate of any mental illness and contribute to long-term negative social, psychological and physical consequences for those affected (APA, 2013). In addition to the clinical eating disorders, disordered eating refers to the cluster of attitudes and behaviours mostly associated with intentional weight loss. On the continuum of eating behaviours, disordered eating lies between balanced, healthy eating and clinical eating disorders. Although eating disorders (i.e., AN and BN) are statistically rare, impacting 1-3.5% of young women (APA, 2000), disordered eating behaviours are far more common with some studies estimating that up to 60% of young women engage in regular episodes of chronic dieting and other disordered eating symptoms (e.g., binge eating, purging, fasting) (Tylka & Subich, 2002). Most disordered eating behaviours are motivated by a desire to lose weight or prevent weight gain, and studies have consistently demonstrated that women who engage in disordered eating behaviours are at greater risk for obesity and binge eating than women who do not diet (Polivy & Herman, 1985; Jacobi et al., 2004). Moreover, women who diet are more likely to report symptoms of anxiety, depression, and body dissatisfaction in comparison with women who do not attempt to restrict their food intake (O'Brien & Vincent, 2003). A cultural norm that encourages thin bodies and dieting has become so widespread that many researchers are calling for a major shift in healthcare away from the promotion of dieting as a 'cure' for obesity and towards more holistic approaches that address the spectrum of disordered eating behaviours and attitudes, including integrating a greater understanding of how social factors impact eating (Nicassio, Meyerowitz, & Kerns, 2004; Travers, 1997).

In terms of women with physical disabilities, clinical observations and published case studies have been the primary sources of information to date regarding the presence of eating disorders in women with physical disabilities. Not only has there been a limited amount of empirical research on this topic, there have been even fewer studies examining the prevalence rates of comorbid ED and physical disability. A notable exception was a study by Neumark-Sztainer and colleagues (1995). This population-based study found that adolescents with a wide range of chronic illnesses were more likely to engage in unhealthy weight control practices and to report greater body dissatisfaction in comparison to those without any chronic illness. More recently, Gross, Ireys and Kinsman (2000) reported that approximately 8% of their sample of young women with physical disabilities (i.e., spina bifida and arthritis) self-reported eating disorder symptoms related to AN or BN, which is higher than the general population. Consistent with these findings, other studies have found higher disordered eating rates among adolescents with cystic fibrosis (Bryon, Shearer, & Davies, 2008) and insulin dependent diabetes mellitus (Kelly, Howe, Hendler, & Lipman, 2005; Rodin & Danerman, 1992; Smith, Latchford, Hall, & Dickson, 2008). Also, several studies have documented the occurrences of eating disorders across various populations, such as blind women (McFarlane, 1989), young women with spina bidfida (Silber, Shaer, & Atkins, 1999), youth with cerebral palsy (Webb, Morgan, & Lacey, 2009), and individuals with asthma (Morgan & Lacey, 1996). There are additional reports of women with nutrition-related chronic illnesses (e.g., celiac disease) and anorexia nervosa; however, for the purposes of this literature review, the focus will be on women with chronic illnesses not related to nutrient intake disturbances.

Besides research examining comorbid ED and physical disability, there is a relevant body of literature examining the occurrence of chronic physical illness prior to the development

of an eating disorder, particularly early onset anorexia. A study from 1969 documented 38 out of 140 mothers reporting "undue physical ill health during their daughter's life before the onset of anorexia nervosa" (Dally, 1969). Patton, Wood and Johnson-Sabine (1986) found greater incidence of prior physical illness in a group of anorexic patients as compared with a group of females with schizophrenia and healthy controls. Watkins, Sutton and Lask (2001) found similar results with prior physical illness being more prevalent in youth with eating disorders than those without. Studies looking at life events prior to the onset of bulimia nervosa corroborate these findings (Welch, Doll, & Fairburn, 1997). Interestingly, the type of prior physical illness, and whether or not it can be related to the alimentary system, did not seem to make a difference. This suggests that the increased risk associated with eating disorder development may be partially explained by general adverse experiences associated with living with chronic physical illness, although the specific underlying mechanisms remain unknown.

The research documenting potential connections between physical disability and/or chronic illness and disordered eating symptoms is complex and raises many unanswered questions regarding etiology and risk. For instance, in one study of 76 women with scoliosis, although over a quarter of the sample were underweight, participants did not score higher on measures of eating disorder pathology (Smith et al., 2008). Given there were no known medical reasons for these women to be underweight, it was hypothesized that their restrictive eating may manifest differently than in women without a physical disability, perhaps motivated by efforts to minimize the appearance-related impact of their disorder as opposed to avoid being overweight or fat. However, it is uncertain if the increased risk for developing disordered eating is related to the presence of a woman's physical disability or health problems. For example, a recent study of adolescents with chronic illness found no differences between those with and

without chronic conditions in terms of eating disorder risk, even after controlling for overall health status (Suris, Michaurd, Akre, & Sawyer, 2008). Alternately, in another study, women with physical disabilities who were most likely to report disordered eating symptoms were those who reported ongoing multiple health issues and high feelings of uncertainty regarding illness course (Gross, Ireys, & Kinsman, 2000). A greater understanding is needed to tease apart the impact of disability, health issues, or other potential influential factors on disordered eating outcomes, particularly how it may play out differently between restricted and uncontrolled eating.

Body Image and Disability Identity

Body image refers to body-related self-perceptions, evaluations, and attitudes (Cash, 2004; Smolak & Thompson, 2009). Body dissatisfaction is a term that captures the negative evaluation of one's body and has been associated with depression, low self-esteem, and social anxiety (Neumark-Sztainer, Paxton, Hannan, Haines, & Story, 2006; Smolak & Thompson, 2009). Polivy and Herman (2002) report that a previous preoccupation and dissatisfaction with weight and shape was a necessary prerequisite to developing an eating disorder in addition to other known known eating disorder risk factors (i.e., history of psychopathology, family discord). Both body dissatisfaction and concern with weight and shape have been shown to predict restrained eating in women (Allen, Byrne, McLean, & Davis, 2008). Unfortunately, most of the literature on body image to date has focused on body dissatisfaction in young women with limited diversity, which has been recognized as a major limitation of the field (Cash & Smolak, 2011).

That being stated, a recent meta-analysis found that female youth with physical disabilities (e.g., scolosis, spina bifida) had slightly higher levels of body dissatisfaction in

comparison to their able-bodied peers (Pinquart, 2013). Factors such as age of illness onset, ethnicity, measurement methods and year of study publication were significant predictors of poorer body image outcomes, suggesting that sociocultural understandings of the construct of body image have impacted past research. In one of the few studies examining ED symptoms in women with physical disabilities, 62% of the sample reported feelings of body dissatisfaction (Gross, Ireys, & Kinsman, 2000), which is equivalent to prevalence rates found in women without disabilities (Spitzer, Henderson, & Zivian, 1999). Further, lower body esteem has been significantly associated with increased severity of functional disability (Taleporos & McCabe, 2001; 2005). Body image concerns have been documented in women with multiple sclerosis (Samonds & Cammermeyer, 1989), rheumatoid arthritis (Gutweniger, Kopp, Mur & Gunter, 1999), and spinal cord injury (Moin, Duvdevany, & Mazor, 2009). Subjectively, women with disabilities report frequently comparing themselves to others without disabilities and seeking frequent external feedback regarding their appearance (de Klerk & Ampousah, 2003).

Despite some findings of body dissatisfaction in women with different physical disabilities, other studies have found that women with disabilities actually seem to worry less about small changes in weight and shape (Ben-Tovin & Walker, 1995). This supposedly protective factor has been shown to increase with the progression of time since initial disability onset (Newell, 2000). In addition, the correlational relationship between disability-related functional limitations and body dissatisfaction is also inconsistent. Some studies have found a direct correlation between functional severity and body dissatisfaction (e.g., Lawrence, Rosenberg, & Fauerbach, 2007), yet these findings have not been consistent. In one study, although only 24% of women with disabilities reported significant functional limitations, over 50% reported dissatisfaction with their body shape and that dissatisfaction was not limited to

body parts impacted by their disability (Gross, Ireys, & Kinsman, 2000). Another study, highlighting that body image findings can shift depending on construct operationalization, found that women with a spinal cord injury were satisfied with the overall functioning of their body while being simultaneously dissatisfied with its appearance (Basset, Martin Ginis, & Buchholz, 2009). Qualities such as a woman's acceptance of disability, social support, perceived health, independence and functionality, and rejection of socially-defined beauty ideals have been found to contribute to a positive body image in those with a physical disability (Baily, Gammage, van Ingen, & Ditor, 2015).

As another important consideration, the relationship between body dissatisfaction and physical disability in women is probably mediated by the timing in which symptoms of a disability emerge (Ben-Tovin & Walker, 1995). Adolescence is frequently cited as a vulnerable time period for body image development due to the physical and psychological changes that can increase focus and meaning on appearance (Wertheim & Paxon, 2011). When this sensitive developmental time period is also paired with an emerging chronic illness, the adolescent's competence to negotiate the demands of this time may be challenged (Yeo & Sawyer, 2005). Rodin, Daneman and deGroot (1983) have postulated it may be that physical illness has damaging effects on body image and self concept, particularly during a time when one's identity and self concept are developing. In a comparison study with adolescents with scoliosis and diabetes, it was found that eating disorder symptoms were only present when the participants first experienced their disabling condition during early adolescence (Smith et al., 2008). Somewhat related to these findings, a population-based study of persons with physical disabilities found those who were born with their disability were reportedly happier and less distressed than were those who acquired their disability during adolescence (Uppal, 2006). As

well, body image dissatisfaction was found to be more prevalent among younger women with a spinal cord injury in comparison to those who were more mature (Moin, Duvdevany, & Mazor, 2009). Taken together, there is some suggestion that the stress of chronic illness may be particularly damaging when the first symptoms occur during adolescence.

Mental Health and Physical Disability

Psychology as a discipline has a long history of pathologizing the presumed poor mental health of the physically disabled community without adequately considering complex sociocultural interactions of disability and mental health (Barnes, Mercer & Shakespeare, 1999). There has been an overreliance on stage theories that conceptualize the psychology of physical disability similarly to grieving a major loss (Olkin, 2001). Inconsistent with these theories, more recent research has indicated that disabled persons have self-esteem levels equal to or, in some cases, greater than, their able-bodied peers, known as the 'disability paradox' (Albrecht & Devlieger, 1999). At the same time, physical disability has legitimately been linked to increased risk for mental health problems. According to Statistics Canada (Crompton, 2011), over one-quarter of women with a chronic physical health problem also have a psychological condition, such as depression or anxiety. In spite of the assorted history of research in the physically disabled, there appears to be a connection between disability and mental health worthy of further exploration.

Both low self-esteem and a history of psychopathological mood disturbances have been linked with greater occurrences of eating disorders (Polivy & Herman, 2002). These topics have each been explored in physically disabled populations; however, findings have not been consistent. Persons with physical disabilities appear to be at a slightly elevated risk for lifetime depression and anxiety symptoms (Brenes, Penninx, Judd, Rockwell, Sewell & Wetherell,

2008; Chevarley, Thierry, Gill, Ryerson, & Nosek, 2006; Turner & Noh, 1988). Turner and McLean (1989) suggest that greater psychopathology in persons with disabilities is best explained through increased chronic stress experienced by this population. On the other hand, other studies have failed to find any association between disability and psychopathology (McDermott, Moran, Platt & Dasari, 2007) and elevated chronic stress (Bramston & Mioche, 2001). Factors such as socioeconomic disadvantage, chronic health problems, stress, low self-esteem and sexuality problems have all been postulated to increase vulnerability to depression and anxiety in disabled women (Nosek, Hughes, & Robinson-Whelen, 2008).

Research exploring disability and self-esteem offers similarly inconclusive findings, with some studies finding general lower self-esteem (Krol, Sanderman, Suurmeijer, Doeglas, van Rijswijk, & van Leeuwen, 1994) and others finding no differences or even higher self-esteem in persons with disabilities (Llewellyn, 2001). Llewellyn & Chung (1997) argue that such studies are flawed given their assumption that a person's physical disability itself is the overriding factor determining a person's self-worth. That being stated, social factors commonly associated with disability, such as unemployment, can certainly contribute to self-esteem issues (Nosek, Howland, Rintala, Young, & Chanpong, 2001). Overall, women with disabilities may be at a greater risk for mood disturbances and feelings of low self-worth, which can also contribute to increased vulnerability to eating disorder symptoms (Polivy & Herman, 2002). Case reports of women with an eating disorder and a physical disability certainly support this association, given that the women described general feelings of unhappiness and low self-worth (Silber, Shaer, & Atkins, 1999; Webb, Morgan & Lacey, 2009). More clarification is needed examining if, like able-bodied women, the increased risks associated with disordered eating in

women with disabilities are related to general psychopathology or if disabled women experience other unique risk factors.

Medical Risks, Obesity and the Pressure to Lose Weight

There are specific medical realities experienced by women with physical disabilities that could contribute to increased vulnerability to developing disordered eating. First, there is some evidence to suggest that birth complications and low birth weight, often found in persons with physical disabilities, increase one's risk for an eating disorder (Favaro, Tenconi, & Santonastaso, 2006). Second, early feeding and mechanical eating problems, again, commonly found in children with disabilities, have also been shown to increase one's risk of eating disorders (Polivy & Herman, 2002); however, no studies have directly linked childhood eating problems in physical disability with later development of an eating disorder or disordered eating symptoms. Third, studies have reported links between secondary health problems and poor psychosocial functioning. For example, chronic pain and fatigue symptoms are associated with depression in persons with muscular dystrophy (Alschuler, Jensen, Goetz, Smith, Verrall, & Molton, 2012) and multiple sclerosis (Alschuler, Ehde, & Jensen, 2013). Although less research has examined disordered eating specifically in relation to health problems, some recent studies have found that severity of chronic pain was associated with increased binge eating (Janke & Kozak, 2012). Similarly, in a sample of overweight/obese adults with arthritis, greater pain severity and functional disability was correlated with lower self-efficacy regarding eating and maintaining weight (Pells et al., 2008).

As previously mentioned, research has found associations between the onset of an eating disorder, particularly anorexia nervosa, and prior physical illness (Dally, 1969; Patton, Wood, & Johnson-Sabine, 1986; Watkins, Sutton, & Lask, 2001; Welch, Doll, & Fairburn,

1997). Some scholars have postulated that unintentional weight loss is the primary explanation for this association (Rodin, Daneman, & deGroot, 1993). In another study of anorexic patients, approximately 7.6% of the cases were preceded by unintentional weight loss with no known prior history of body and shape concerns or restrained eating (Brandenburg & Anderson, 2007). The unintentional weight loss was cited as being caused by a type of medical condition. It appears that the experience of weight loss, whether or not that weight loss is intentional, can be a powerful trigger for restrictive eating for some women.

In a recent study, it was deemed that although adults with physical disabilities make up only seven percent of the U.S. population, those physically disabled who are also obese accounted for over 50% of the healthcare burden attributable to obesity (Peterson & Mahmoudi, 2015). These statistics highlight the mounting pressure and concern over curbing obesity rates in the disabled population. Obesity and overweight status have also been shown to be significant risk factors for disordered eating (Jacobi et al., 2004) as there is tremendous pressure on overweight individuals to engage in dieting behaviours. Adults with a disability are 53% more likely to be obese than those without disabilities and the highest risk occurs among adults with mobility difficulties (38.5% vs. 25%) (Crompton, 2011; Fox, Swanson & Krahn, 2012). Further, in another study, over 50% of adults with physical disabilities reported a high concern regarding their weight (McColl & Skinner, 1995).

Persons with physical disabilities are at risk for a number of factors that increase their vulnerability to weight gain, including mobility problems, low physical activity, poor socioeconomic status, limited access to healthful foods, and increased dependence on others (e.g., parents, attendants) for meal purchasing and preparation (Fox, Witten, & Lullo, 2014). With regards to physical activity, women with disabilities in Ontario reported being half as

likely as their peers to be physically active on a daily basis, with over two-thirds being classified as completely inactive (Crompton, 2011). These low levels of activity have been documented early in the life of a child with a disability. For example, primary school students with physical disabilities have the lowest levels of physical activity, even among those who take physical education classes (Sit, McManus, McKenzie, & Lian, 2007). Access to healthy foods has also been highlighted as a barrier confronting women with physical disabilities in maintaining their weight (Webber, Sobal, & Dollahite, 2007). Taken together, studies (e.g., Fox, Witten, & Lullo, 2014; Odette et al., 2003) have documented the presence of both internal and external barriers specific for women with physical disabilities preventing engagement in wellness activities (i.e., health promoting behaviours), including medical (e.g., chronic pain and fatigue), economic (e.g., high cost of transportation, healthy foods, gym memberships), structural/environmental (e.g., inaccessible gym locations, inadequately trained support staff) and systemic (e.g., inadequate inclusion into health prevention programming, limited information and research).

Regardless of the actual health risks or the specific causes, weight gain in the disabled population can have a substantial perceived negative impact, thereby motivating self-efforts to lose weight. Women with disabilities are frequently prescribed medication that promotes weight gain (Minihan, Fitch, & Must, 2007). A study by Fornari and colleagues (2001) found that weight gain due to prescription steroid use predated the onset of an eating disorder in some women. In a qualitative study of eating disorders in young women with spina bifida, all five of the women interviewed reported being advised by their doctor to lose weight to maintain their current mobility level prior to their food restrictive practices (Silber, Shaer, & Atkins, 1999). Although more research is needed, there is no doubt a connection between secondary health

complications of living with a physical disability and risk for developing unhealthy weight control practices.

Quality of Life: Sociocultural Factors of Disability

Interacting with both medical and psychological risk factors, living with a disability has certain social and cultural associations that may contribute to the development of disordered eating and other mental health problems (e.g., depression, anxiety, low self-esteem). Women with disabilities often experience limited and/or compromised social participation for a variety of reasons related to physical, medical, attitudinal, and environmental barriers. According to a Statistics Canada report (Crompton, 2011), disabled women are nearly twice as likely as other women to live alone (26% vs. 14%), and are only about half as likely to live with a spouse and children (15% vs. 28%). Moreover, in terms of social support, 64% of adults with a disability reported that they do not socialize with friends as much as they desire due to environmental obstacles, physical impairments, and attitudinal barriers (Kaye, 1997). Lack of social participation and community exclusion can further extend to issues of underemployment, housing, and education (Devereux, Bullock, Gibb, & Himler, 2015). Disabled women in Ontario are not as educated as other women, even after controlling for age (e.g., 22% vs. 32% have a university degree) (Crompton, 2011).

It has been well documented that reports of social anxiety and childhood teasing are common among individuals with an eating disorder (Polivy & Herman, 2002). A childhood history of torment/teasing, surrounding weight and shape, is also common for women with spina bifida with an eating disorder (Silber, Shaer, & Atkins, 1999). Furthermore, living with a physical disability negatively impacts children who often report experiences of social isolation and stigmatization from their peers (Lee & Rodda, 1994). Although social isolation and teasing

are not common to all youth with disabilities, they can have lasting effects that challenge optimum psychosocial development.

In terms of sexual and gender identity, disabled women are frequently viewed as asexual and genderless in society (Curry et al., 2009). These stereotypes can have a lasting and damaging impact, including reported difficulties in dating or finding intimate partners (Taleporos & McCabe, 2003), inadequate sexual education (Curry et al., 2001), increased vulnerability to abuse (Nosek, Foley, Hughes, & Howland, 2001), and compromised sexual health services (Dotson, Stinson, & Christian, 2003). Silber, Shaer and Atikins (1999) have suggested that sexual immaturity is another avenue to explain why individuals with physical disabilities may be vulnerable to eating disorders. Within the eating disorder literature, it has been theorized that eating disorders in young women serve to delay sexual maturation in an effort to avoid becoming an adult (Killen et al., 1996). Studies find a similar avoidance of sexuality in persons with disabilities; however, this avoidance is less psychologically motivated and more related to social stigma and physical limitations (Taleporos & McCabe, 2003). In line with this theory, adolescents with disabilities have demonstrated lower sexual esteem, decreased overall knowledge of sex (Berman, Harris, Enright, Gilpin, Cathers, & Bukovy, 1999), and more negative attitudes surrounding sex (McCabe, 1999) than do those without disabilities. Despite similar sexual needs as persons without disabilities, young women with physical disabilities have been shown to have significantly lower sexual satisfaction and sexual self-esteem (Moin, Duvdevany, & Mazor, 2009). Taken together, there is some evidence to suggest that women with disabilities experience greater challenges around sexuality than those without disabilities, which may further contribute to their increased risk for disordered eating.

Family discord has been frequently cited as a risk factor for eating disorders (Polivy & Herman, 2002). More specifically, family over-enmeshment/over-involvement is a common theme both for eating disordered individuals (Shoebridge & Gowers, 2000) and persons with disabilities (Holmbeck et al., 2002). An unfortunate consequence of parental over-involvement amongst children with disabilities is that they often develop diminished autonomy and self-efficacy (Holmbeck et al., 2002). Polivy and Herman (2002) theorized family discord contributes to potential eating disorder development through its attack on an individual's identity and feelings of control. Again, more research is needed to fully understand this relationship but it seems as though an overprotective family life may contribute to a young women's overall risk for eating disorder development.

Next, a widespread cultural preference for thin bodies has had a strong impact on all women and women with disabilities are no exception. Women with disabilities report concern about the body weight, shape and size similar to other women (Young et al., 1994); however, they also report additional disability-specific concerns and thus often feel a need to 'dress to impress' (Watson, 1999). For instance, women with disabilities have reported frequently engaging in appearance modification as a form of compensation in order to ameliorate the stigma of disability (Kaiser, Wingate, Freeman, & Chandler, 1987). Certainly, additional case reports have corroborated these findings in which women with both an eating disorder and physical disabilities reported pressure to lose weight in order to be better liked by peers and romantic partners (Silber, Shaer & Atkins, 1999). Not only do women with disabilities face the societal pressures to be thin, but they also must deal with a culture that devalues disability and limitations (Luborsky, 1994). Women with disabilities have expressed feelings of invisibility,

undesirability and feeling like a burden on others (Zitzelsberger, 2005) as well as incompetence and low autonomy (Luborsky, 1994).

Lastly, women with physical disabilities experience high rates of sexual assault, intimate partner violence and abuse (Plummer & Findley, 2012). Although larger-scale research studies into the rates of trauma/abuse for disabled women have been relatively scarce, smaller studies found that women with disabilities are more vulnerable to abuse, particularly caregiver abuse (Nosek, Howland, & Hughes, 2001). Some studies have reported that disabled women were up to four times more likely to have experienced sexual abuse in comparison to women without disabilities (e.g., Martin et al., 2006). In a recent review, it was concluded that disabled women were, at minimum, equally likely to experience abuse in comparison to nondisabled women, yet were less likely to be identified and, as a result, were more likely to experience barriers in removing themselves from the abusive environment and receiving appropriate supports (Plummer & Findley, 2012). Experiences of childhood trauma and abuse, sexual abuse in particular, have been linked to eating disorders, including disordered eating symptoms, and body dissatisfaction (Caslini et al., 2016; Preti, Incani, Camboni, Petretto, & Masala, 2006). Therefore, a greater understanding of these risks and vulnerabilities for disabled women is warranted.

Integration of Disability Studies

Disability studies emerged out of criticisms of traditional research, treatment and other scholarly work that pathologizes disability as a limitation or deficiency and further contributed to the exclusion of disabled persons (Oliver, 1990). Disability studies scholars advocate for the inclusion of disabled persons in all research or initiatives involved with their care, study and provision of services, captured by the slogan *Nothing about us, without us*. The social model of

disability, developed by disabled people in response to the dominance of the medical model, draws a distinction between *impairment*, which is defined as a physical lack or defect pertaining to the body, such as a missing limb, and *disability*, which is caused by the relationship between people with impairments and the non-accommodating and exclusionary social and physical environments with which they interact (UPIAS, 1976). To expand understanding of the relationship between eating, weight and body image distress and physical disabilities, this dissertation research embraces Carol Thomas' formulation of the social relational model of disability, which conceptualizes disability as produced within social contexts, while also promoting recognition of the embodied and experiential aspects of disability. The perspective acknowledges what Thomas identifies as "impairment effects," (Thomas, 1999) which are difficulties (pain or fatigue) stemming directly from the impairment itself. Yet, according to Thomas's model, even difficulties arising from impairment cannot be fully detached from social influences because one's environment often exacerbates or ameliorates the effects of impairment. Research conducted under this approach encourages Community Based Participatory Research (Drum et al., 2009), which ensures disabled persons are involved in the research process and that participant voices are represented in a manner that promotes social change.

Disability studies scholars draw a distinction between person- and identity-first language. Under the medical model of disability (APA, 2010), recommendations have been put forward with regards to person-first language, meaning the speaker/writer addresses the individual first, followed by their impairment (i.e., person with a physical disability). Psychologists working in rehabilitation advocate that person-first perspectives can reduce stigma and stereotyping towards those with disabilities (Peers, Spencer-Cavaliere, & Eales,

2014). On the other hand, identity-first language, inspired by the social model, attests that because disability is understood as a culturally composed and shared social identity, similarly to racialized peoples (e.g., Black woman), there should be no implication of a secondary disease or impairment (i.e., Disabled person) (Davis, 2013). In the following dissertation, I will use both person- and identity-first language, as recommended recently by Dunn and Andrew (2015), as a way to address the concerns of disability groups as well as maintain scientific and professional rigor.

Study Rationale

There are a number of studies that suggest that women with physical disabilities are an at-risk population for symptoms of disordered eating and body dissatisfaction. Rates of eating disorders in this population appear to be higher than those in the general female population; however, there have been limited large-scale studies corroborating these findings, particularly with regards to comparing the prevalence, frequency and severity of a wide range of disordered eating symptoms (e.g., restrictive dieting, purging, etc.). Also, no study to date has examined the prevalence of binge eating for those with physical disabilities. Given the increased prevalence of binge eating in the general population and the concerns associated with obesity risks for those with disabilities, the lack of research is a limitation in the literature. Furthermore, no studies to date have offered potential explanations for why disability may be correlated with increased risk for disordered eating. It is unclear how physical disability and other confounding factors, such as the existence of health problems, may impact the presentation of disordered eating. Overall, limited information exists surrounding any manifestation and identification differences of disordered eating in disabled women as well as the need and appropriateness of

current support, treatment and prevention programs addressing disordered eating and healthy living in general.

Overview of Study Design

The dissertation was conducted in two separate studies as a basic sequential mixed methods design. In sequential mixed designs, data collected and analyzed from one phase of the study are used to inform the other phase of the investigation. For this dissertation, Study 1 consisted of a quantitative survey comparing problematic eating measures and associated psychological indices of women with and without physical disabilities. Next, Study 2 was a qualitative interview study that used grounded theory (methodical hermeneutics) to examine the experiences of eating for women with physical disabilities on a subset of individuals who endorsed high levels of current problematic eating behaviour in Study 1. A mixed methods design was selected for participant enrichment (i.e., enhancing opportunities to select participants for recruitment who are most appropriate for the study – those who had high scores on disordered eating and body dissatisfaction scales), instrument fidelity (i.e., assessing the appropriateness of reliable and valid disordered eating, mental health symptoms and body/self esteem scales for participants with physical disabilities in Study 1), and significant enhancement (i.e., enhancing the richness of data for interpretation and usefulness of findings by using the strengths of differing methods to understand disordered eating in women with physical disabilities) (Collins, Onwuegbuzie, & Sutton, 2006). Further, Johnson, Onwuegbuzie, and Turner (2007) discusses that another purpose for mixed methods research can be to avoid oppression and promote social justice by allowing participants to explore the phenomenon in their own voice. Given the marginalization experienced by women with physical disabilities, the mixed methods approach deemed most suitable combined quantitative prevalence rates with

standardized measures, as well as qualitative interviews that further capture the unique struggles of this population.

STUDY 1

Quantitative Study Objectives

Specific objectives of Study 1 are as follows:

1. To compare the frequency and severity of problematic eating (i.e., binge eating, purging, severe restriction, chronic dieting), body dissatisfaction, and associated psychological indices (i.e., anxiety, depression, body esteem, self esteem) of women with physical disabilities to those of women without physical disabilities matched on age.
2. To assess the role of disability severity in the development and maintenance of problematic eating and mental health difficulties in a sample of women with physical disabilities.
3. To determine the impact of body dissatisfaction and body mass index (BMI) on outcomes of disordered eating and mental health in a sample of women with physical disabilities.

Hypotheses of Study 1

Hypothesis 1. Consistent with previous studies on eating disorders in women with chronic physical disabilities (Bryon, Shearer, & Davies, 2008; Neumark-Sztainer et al., 1995; Walkins, Sutton, & Lask, 2001), it is predicted that women with physical disabilities will have higher rates of disordered eating and body dissatisfaction as well as associated psychological indices of mental health (i.e., depression, anxiety, self-esteem) in comparison to women without disabilities.

Hypothesis 2. Consistent with past case reports of disabled women with eating disorders (Silber, Shaer, & Atkins, 1999; Webb, Morgan & Lacey, 2009), it is hypothesized that greater

reported severity of disability will be associated with increased levels of disordered eating and body dissatisfaction in women with physical disabilities.

Hypothesis 3. Body dissatisfaction is a well-supported core risk factor for disordered eating in women without disabilities (Polivy & Herman, 2002). It is expected that after controlling for BMI, greater body dissatisfaction will be associated with greater levels of disordered eating also in women with physical disabilities.

Method

Participants

Participants included were 138 women who self-identified as having a physical disability and/or significant mobility impairment. These women were recruited throughout the community in Toronto, Ontario as well as through Internet websites and listserves. Most of the participants were recruited through a call for participation (Appendix A) through social networking sites, disability-related email listserves, and through posting flyers in areas where women with physical disabilities could be found (e.g., rehabilitation hospitals, local community centres). Participants were excluded if they did not meet the inclusion criteria (see below) as well as those with 50% of more survey data missing. Six participants were removed who fell outside of the desired age range (16 to 40). The maximum age range was capped at 40 in order to capture the population of young women at highest risk for developing disordered eating and body image problems (Polivy & Herman, 2002). Fourteen participants were removed because they did not have a physical disability that significantly impacted their mobility and/or appearance. The final sample consisted of 114 women with physical disabilities (M = 26.74, SD = 5.84). A comparison group, consisting of 112 women aged 18-40 (M = 26.36, SD = 6.23) who do not have a physical disability, were recruited through York University's Introductory

Psychology class, which is a large, diverse pool of undergraduate students. Three participants were removed due to excessive missing data (>50%). An additional 14 participants aged 17 and 18 were removed at random in order to provide an age-matched sample in comparison to the group of women with physical disabilities.

Procedure

The study received ethics approval from York University. All participants gave informed consent (see Appendix B). The call for participation for women with disabilities provided a website link to Surveymonkey to access the online battery of measures. Participants with disabilities were offered an opportunity to participate in a draw to win an I-Pad2 for their involvement in the study. The control group was recruited through York University's Undergraduate Research Participant Pool and earned one course credit for their participation. All participants were asked to participate in a survey on 'understanding disordered eating in young women'. If they agreed, they were asked to complete the same battery of self-report measures, except when noted. The questionnaires, outlined below, were completed in approximately 30 to 45 minutes.

Measures

Demographics. All participants were asked to report their age, height and weight, ethnicity, marital status, annual income as well as their educational and occupational status.

Disability. Within the sample of women who identified as having a physical disability or significant mobility impairment, disability was assessed using multiple measures in an effort to capture the different models of understanding disability (e.g., social, medical, functional, etc.). First, women were asked to indicate the medical classification or diagnosis associated with their physical disability. They were further asked to report the number of years that they

have lived with their disability (since first symptoms presentation) and whether their disability is congenital (e.g., disabled since birth) or acquired. Women were also asked to report the type of mobility aids (e.g., wheelchair, cane, walker, etc.) that they use on a day-to-day basis.

Functional ability (i.e., objective disability) was assessed using the Rapid Disability Rating Scale (RDRS, 1967). The RDRS was developed as a research tool to provide rapid assessment of functional capacity by care professionals in the elderly or among persons with chronic conditions in a hospital, nursing home, or rehabilitation setting. The scale asks participants to report how much assistance they require (e.g., eating, walking) and the level of impairment they experience (e.g., presence of medications, special diet) across a broad range of different activities. The scores in this study range from 8 to 24, with higher scores being indicative of greater disability. The scale was modified for this study to be used as a self-report measure. As shown in Appendix C, some activities were removed from the scale that could not be assessed using self-report (e.g., mentally confused, uncooperative, etc.). The scale has demonstrated adequate reliability and validity when used by nurses or other trained caregivers (Linn & Linn, 1982). The Cronbach's alpha (α) within the sample of women with physical disabilities was $\alpha = 0.50$, which is representative of the diverse abilities (from walking to hearing and sight) measured by the scale.

Next, participants were asked to indicate how much caregiving assistance they required for activities of daily living, transfers (e.g., moving from wheelchair to bed), meal preparation, and eating on a scale from (1) 'No assistance required/completely independent' to (4) 'Full assistance required' as an additional measure of functional disability. These items were compiled by myself in the absence of other suitable measures (see Appendix C for a full listing of items under Demographics).

To measure subjective feelings of disability, participants were asked to rate the perceived severity level of their disability in terms of mild, moderate, or severe. In addition, participants were asked to report to what extent they felt their disability impacted different aspects of their life (i.e., physical appearance, physical ability, social, environmental, attitudinal/negative societal perceptions, emotional, psychological) from 'not at all' to 'significantly'. A total score of subjective disability ranking was obtained by summing each category ranking of disability. Finally, participants were asked to rank their overall health in the past 30 days with one indicating 'poor health' and 10 indicating 'excellent health'. These questions were captured in the Demographics section found in Appendix C.

Eating History. All participants were asked to report whether or not they were ever advised by a health care provider and/or their family, friends, or caregivers to lose weight. If they reported 'yes', then further questions were asked including who asked the participant to lose weight, when (i.e., year), how many times, and how much weight approximately in pounds that they were advised to lose. Participants were also asked to indicate whether or not they felt that they needed to lose weight ('yes' or 'no'). If they reported 'yes', follow-up questions included inquiring about their motivations to lose weight (e.g., for appearance, health or other reasons) as well as approximately how much weight they felt they needed to lose in pounds. Finally, participants were asked to report if they had ever been diagnosed with an eating disorder in the past and, if so, to report what type of eating disorder (i.e., anorexia nervosa, bulimia nervosa, binge eating disorder, eating disorder not otherwise specified, other, and unknown) and the year of diagnosis.

Dietary Restraint. The Restraint Scale-Revised (RRS: Polivy, Herman, & Howard, 1988) was given to all participants and measured reported level of restrained eating (i.e., dieting

behaviour). It consists of ten scored Likert-scale items that measure a participant's tendency to restrict food and worry about body size/shape. The Restraint Scale is widely used and has been shown to be reliable and valid (e.g., Allison, Kalinsky, & Gorman, 1992). Although the Restraint Scale is often used to categorize participants as restrained or unrestrained eaters, this study used the total score as a continuous variable in order to capture the full-range of dietary restraint behaviours and attitudes. The measure demonstrated good internal consistency in the present study ($\alpha = .83$).

Disordered Eating. Disordered eating was assessed in all participants using three self-report measures. First, the Eating Disorder Examination Questionnaire (EDE-Q: Fairburn & Cooper, 1993) is a widely used 36-item self-report measure that assesses the presence and severity of eating pathology over the past 28 days. The scale consists of a global score as well as four subscales (restraint scale, eating concern scale, weight concern scale and shape concern scale). The scale has shown good test-retest reliability in a sample of binge eating disorder patients (Grilo, Masheb, Lozano-Blanco, & Barry, 2004) in addition to adequate reliability and validity for the assessment of eating disorder symptoms (Berg, Peterson, Frazier, & Crow, 2012; Fairburn, Cooper, & O'Connor, 2008). In the current sample, the internal consistency of the EDE-Q was very good ($\alpha = .95$).

Second, eating disorder symptoms were also assessed using the Eating Attitudes Test (EAT-26: Garner, Olmsted, Bohr, & Garfinkel, 1982). The EAT-26 consists of an index of symptoms frequently observed in persons with clinical eating disorders. The scale has been widely used both in clinical and nonclinical samples. It has also been used as a screening tool for eating disorders and its accuracy (90%) in comparison to a diagnostic interview is well supported (Mintz & O'Halloran, 2000). The scale's 26 items are scored on a 6-point Likert

scale. Higher scores are indicative of higher levels of disordered eating with scores above 20 considered at being greater risk for eating disorders (Park & Beaudet, 2007). Cronbach's alpha coefficient for the EAT-26 global score scale in the present study was $\alpha = .86$.

Lastly, due to a lack of previous research assessing binge eating for those with disabilities, a specific binge eating severity scale was included: the Gormally Binge Eating Scale (GBES: Gormally, Black, Daston, & Rardin, 1982). The GBES measures behavioural aspects of binge eating (e.g., eating a large amount of food) as well as feelings and thoughts that are associated with binge eating (e.g., guilt). It consists of 16 items in which participants are asked to select the statement that best reflects their attitudes and behaviours about eating. Higher scores are indicative of more binge eating problems, with scores over 27 suggesting severe binge eating while scores under 17 reflect mild or no binge eating problems. The GBES has shown adequate reliability (Greeno, Marcus, & Wing, 1995) and internal consistency (Gormally et al., 1982). Cronbach's alpha coefficient for the GBES scale in the present study was $\alpha = .94$.

Depression. The Beck Depression Inventory-II (BDI-II: Beck, Steer, & Brown, 1996) was given to all participants. The BDI-II is a measure of depressive symptoms over the past two-weeks. Participants score each item on a 4-point Likert type scale. Higher scores are indicative of more severe depression as suggested by the BDI-II's use of DSM-IV criteria for depression, although the measure is not diagnostic on its own. Total BDI-II scores of 0-13 are considered to be within the minimal range, 14-19 indicates mild depression, 20-28, moderate, and scores from 29-63 reflects severe depression. The high internal consistency, reliability and discriminant validity of this 21-item self-report scale has been confirmed (e.g., Dozois, Dobson,

& Ahnberg, 1998). The internal consistency of the measure in this study was also found to be very good (α = .94).

Anxiety. The Beck Anxiety Inventory (BAI: Beck & Steer, 1993a) was given to all participants. The BAI is a 21-item self-report measure of anxiety symptoms over the past month, such as sweating not due to heat or fear of the worst happening. Participants are asked to rate the severity of each symptom on the scale using a 4-point scale where higher scores indicate greater symptoms of anxiety. Total scores on the BAI under 21 suggest no or mild anxiety, scores that ranger between 22-23 reflect moderate anxiety, and scores over 36 are indicative of severe anxiety. The BAI is widely used and has shown good reliability and validity (Beck & Steer, 1990). The internal consistency in the sample was α = .93.

Self-Esteem. The Rosenberg Self-Esteem Scale (RSES: Rosenberg, 1965) was given to disabled and nondisabled participants. It is a 10-item scale that measures global self-esteem, typically defined as one's feeling of overall worthiness as a person (Baumeister, 1993). It consists of a set of statements where participants indicate on a 4-point scale the degree to which every item represents the best description of themselves. The total score can range from 0 to 30 with higher scores representing higher levels of self-esteem. The RSES is widely used and has demonstrated adequate reliability, stability, and validity (Ferring & Filipp, 1996; Whiteside-Mansell, & Corwyn, 2003). Cronbach's alpha coefficient for the RSES scale in the present study was α = .92.

Body Dissatisfaction. The Body Esteem Scale (BES: Franzoi & Shields, 1984) measures feelings and evaluations of their body and was given to all participants. There are three subscales which measure sexual attractiveness, weight concern, and physical condition. Participants were asked to rate 35 individual body parts and functions on a 5-point Likert-type

scale that ranges from (1) ‘Have strong negative feelings’ to (5) ‘Have strong positive feelings’. Higher scores represent more positive feelings about weight and body size. The scale has demonstrated adequate psychometric properties in samples of young women (Franzoi & Herzog, 1986). The internal consistency for the present study was α = .94.

Appearance Investment. The Appearance Schemas Inventory-Revised (ASI-R; Cash, Melnyck, & Hrabosky, 2004) measures participant level of psychological investment in their physical appearance and was given to all participants. It consists of 20 items rated on a 5-point Likert-type scale ranging from (1) ‘strongly disagree’ to (5) ‘strongly agree’. Although the measure includes two subscales, only the total score was used in the current study, with higher scores representing greater investment in one’s body image. Example items include ‘Before going out, I make sure that I look as good as I possibly can’ and ‘If I dislike how I look on a given day, it’s hard to feel happy about other things’. Cronbach’s alpha coefficient for the ASI-R in the present study was α = .90.

Body and Sexual Esteem. The Physical Disability and Sexual Esteem Scale (PDSES: Taleporos & McCabe, 2002) was given to participants with physical disabilities only. The scale measures participant feelings about their body and their sexuality related to their physical disability. The 10-item questionnaire consists of three subscales: sexual esteem (e.g., ‘I feel my disability interferes with my sexual enjoyment’), body esteem (e.g., ‘I would do a body swap with an able bodied person if I could’), and perceived attractiveness to others (e.g., ‘It is harder to find a sexual partner when you have a disability’). The PDSES demonstrated reliability and validity in samples of persons with different types of physical disabilities (Taleporos & McCabe, 2002). The internal consistency for the current study sample of women with physical disabilities was α = .87.

Data Analysis

Data were examined for multicollinearity, violations of normality, and outliers. Test assumptions were met and there were no outliers that were significantly impacting the data. The Benjamini-Hochberg Procedure was used to control for the false positive rate due to multiple comparisons (Thissen, Steinberg, & Kuang, 2002). The Benjamini-Hochberg has certain advantages in maximizing power while correcting false positives over the conservative correction of the Bonferroni Procedure (Williams, Jones, & Tukey, 1999). Prior to analyses, one-way Analyses of Variance (ANOVA) were conducted to confirm that no preexisting statistical differences existed between groups (women with physical disabilities and those without) in terms of mean age or body mass index (BMI). Violations to the assumptions of homogeneity of variance test were corrected using the Welch statistic (F_w). Missing responses from self-report questionnaires were replaced with the mean when the participant completed at least 70% of the questions in order to obtain a total scale score (Dong & Peng, 2013). Preliminary analyses were conducted to describe the sample of women with physical disabilities in relation to the control group (women without physical disabilities) as well as to assess the relationship of predictor and dependent variables. These included examining Pearson correlations, Chi-square tests, and One-way ANOVAs. Chi-square tests with Cramer's V as the indicator of effect size were conducted to compare demographics (e.g., ethnicity, education) between women with and without physical disabilities.

Hypothesis 1. Frequency of symptoms and behaviours were compared between women with and without physical disabilities. ANOVAs were then conducted to compare women with physical disabilities with the control group on measures of disordered eating (RRS, GBES, EDE-Q), body esteem (BES), mental health status (BDI-II, BAI, RSES) and overall reported

health status (health rankings). The Benjamini-Hochberg Procedure suggested $p = 0.033$ to account for the multiple outcome variables (nine in total).

Hypothesis 2. To test the hypothesis that greater disability severity is associated with higher disordered eating rates and poorer mental health indices among women with physical disabilities, a series of linear regression analyses were conducted. Based on correlational analyses (Table 1), the dependent variables sexual esteem (PDSES) and appearance investment (AI) were removed from the analyses due to very low correlational data between any of the predictor variables, and the EAT-26 measure of disordered eating was removed as it was deemed unnecessary given the high correlation and similar construct definition to the EDE-Q measure of disordered eating. The number of participants was deemed adequate for the number of variables entered into the regression models. The model tested different disability predictor variables, including subjective disability rating (total score), functional disability level (RDRS), and reported overall health ranking. The outcome variables included measures of disordered eating (EDEQ, GBES, RRS), body esteem (BES) and mental health symptoms (RSES, BDI-II, BAI). The Benjamini-Hochberg Procedure suggested $p = 0.043$ to account for the multiple outcome variables.

Next, some exploratory analyses were conducted to further understand the impact that disability type and length of time living with a disability have on disordered eating, disability severity and mental health symptoms. A one-way ANOVA was conducted to compare dependent measures (RRS, EDEQ, GBES, BES, BDI-II, BAI, RSES, Health ranking, Disability ranking, RDRS) between women with acquired and congenital disabilities. A multiple regression analysis was also employed where number of years living with a disability was tested as a predictor variable on the same outcome variables named above. The number of

participants was deemed adequate for the number of variables entered into the regression models. The Benjamini-Hochberg Procedure determined a significance level of 0.030.

Hypothesis 3. A series of linear regression analyses were also used to test the hypothesis that higher body esteem (BES) predicted less disordered eating (RRS. GBES, EDEQ) and lower scores on measures of mental health issues (BDI-II, BAI, RSES), while controlling for BMI. The number of participants was deemed adequate for the number of variables entered into the regression models. The Benjamini-Hochberg Procedure suggested a significance level of 0.050.

Results

Demographics

There were no significant statistical differences between the group of women with physical disabilities and the comparison group in terms of age, $p = 0.07$, marital status, $p = 0.09$, or reported annual income, $p = 0.19$. Approximately 62% of the sample of women with disabilities reported that they were single or widowed and 37% were currently in a relationship or married. In terms of socio-economic status, 28% of the sample reported earning $10,000 a year or less, 46% reported earning $10, 000-$50, 000 per year, and 8% reported earning over $55, 000 per year. The ethnic distribution of the sample of women with a physical disability was 80% White, 8% Asian, 3% Black, 8% Hispanic, and 1% other ethnic distribution. In comparison to the control group, the sample of women with physical disabilities were overall less ethnically diverse, $p < 0.001$, $V = 0.49$. The targeted sample also reported a higher education status than women without physical disabilities, $p = 0.003$, $V = 0.25$. Approximately 61% of the sample of women with physical disabilities had a college or university degree, while only 10.5% had their high school diploma or lower. In terms of occupational status, 20% were

unemployed, 41% were full or part time students, and 47% were employed (full-time, part-time or casual). Twenty-four percent of the sample reported that they received disability benefits as their main source of income. The majority of the sample lived independently within the community (50%), while another 34% lived with parents or other family. Seventeen percent of the sample indicated that they lived in the community with assistance from attendant services (e.g., supportive housing, outreach, direct funding).

Disability

Within the sample of women with physical disabilities, the most common diagnoses included: neuromuscular disorder (32%), cerebral palsy (24%), spina bifida (11%), musculoskeletal disorder or spinal cord injury (11%), arthritis (8%), amputation (4%), and other birth defects or acquired disorders (11%). Seventy-five percent of participants reported that they have had their disability since birth. Years of living with a physical disability ranged from one to 39, with the mean number of years living with their disability being 23.88 (SD = 9.46). The women reported using a variety of mobility/assistive devices on a regular basis. Sixty-seven percent of the sample reported primarily using a wheelchair for mobility, 12% reported using walker/cane/crutches, and 21% do not use any mobility devices. In terms of daily assistance, Figure 1 depicts how much assistance the women in the sample generally receive. Forty-eight percent of the sample reported needing 'moderate' to 'full' assistance for transfers (e.g., moving from bed to wheelchair). Approximately 26% of women need 'full' assistance for activities of daily living (e.g., showering, toileting, dressing) and 25% for meal preparation (e.g., cooking, preparing food). In contrast, only 5% of the sample reported requiring 'full' assistance for eating, with the majority of participants (70%) reporting that they needed no assistance.

Disability was assessed with a variety of measures in order to fully capture various ways a woman can feel 'disabled' in her life. The majority of participants rated the overall impact of their disability on their life as 'moderate' (46%), whereas, 21% rated their disability as 'severe' and 32% rated as 'mild'. In terms of physical appearance, 60% of women reported that their disability 'moderately-significantly' impacted their appearance. Figure 2 depicts how disabled participants reported feeling in different areas of their life (i.e., physically, emotionally, socially, psychologically, environmentally, attitudinally). Mean group comparisons found that women felt most disabled 'physically' (i.e., 'Are the actions you take or wish to take limited by physical restrictions?') and 'environmentally' (i.e., 'Does your disability affect your access to resources, community settings, transportation, and/or education/employment?'). In contrast, women felt least disabled 'emotionally' (i.e., Does your disability affect your mood, temperament, and/or disposition?') and 'psychologically' (i.e., 'Does your disability affect your thoughts and/or your feelings?'). A total score of subjective disability (how disabled women felt across different aspects of their life) was calculated for all women. According to the Rapid Disability Rating Scale, which assesses level of functioning and disability according to the rehabilitation model, the overall sample of women with physical disabilities was 'minimally' disabled ($M = 11.96$, $SD = 2.47$). When asked to rank their overall health status, women with physical disabilities in this sample rated their health as lower ($M = 6.82$, $SD = 2.22$) as compared to women without physical disabilities ($M = 7.43$, $SD = 1.89$), with a small effect size, $p = 0.03$, $\eta_p^2 = 0.02$).

Disordered Eating

In the sample of women with physical disabilities, 18% had an EAT-26 score over 20 in comparison to 17% of those without a physical disability, which is highly indicative of the

presence of an eating disorder (Garner, Olmsted, Bohr, & Garfinkel, 1982). Approximately 7.7% of participants with physical disabilities reported that they have used vomiting as a means for purging to control their shape or weight in the past four weeks in comparison to 2.7% of those without disabilities. In addition, 6.8% (vs. 9.8%) reported using laxatives and 4.3% (vs. 8%) reported using diuretics in the last four weeks as a means to control their weight or shape. In terms of over-exercise, 20.5% of participants reported 'exercising hard' in the past four weeks to control their weight/shape in comparison to 32% of those without disabilities. Twenty-nine percent of participants reported engaging in objective binge eating (eating an unusually large amount of food and a feeling of loss of control) in the past four weeks in comparison to 35% of those without disabilities. Table 2 provides a summary of scores for women with physical disabilities on measures that assess disordered eating and body dissatisfaction.

In terms of Body Mass Index (BMI) of the sample of women with physical disabilities 17% were classified as underweight, 28% were overweight, and 13% would be classified as obese or over according to the International Classification of the World Health Organization (1995). In comparison to those without disabilities, 10% were underweight, 16.5% were overweight and 11.5% were obese or over. The mean BMI of the group of women with physical disabilities was 24.22 (SD = 9.03). There was no statistically significant difference between the group of women with physical disabilities and those without; however, there was a significant difference between the variance in BMI, F (1, 206) = 5.87, p = 0.016. The BMI scores of women with physical disabilities had a much greater range and variance than did those of women without physical disabilities. In other words, there were many more participants with disabilities who were on the lower or upper extremes of the BMI spectrum. Thirty percent of the sample of women with physical disabilities endorsed that they had been advised by a health

care provider (e.g., doctor, nurse, dietician) to lose weight. The amount of weight they were told to lose ranged from five to 100 pounds, with a mean suggested weight loss of 36.94 pounds (*SD* = 28.86). In addition, 48% of the sample had been advised by family members, friends, or caregivers (i.e., attendants) to lose weight. Sixty-three percent of the sample reported that they themselves felt that they currently needed to lose weight. The amount of weight they felt they needed to lose ranged from one to 150 pounds, with a mean of 25.67 (*SD* = 30.07). Women with a physical disability did not differ significantly from the comparison group in terms of frequency of being told to lose weight nor self-reported need for weight loss.

Hypothesis 1. No significant differences were found between women with physical disabilities and women without in terms of restrained eating, disordered eating, and binge eating. Women with physical disabilities reported higher levels of body dissatisfaction (*M* = 114.50, *SD* = 25.08) than did women without physical disabilities (*M* = 101.15, *SD* = 21.37) with a small effect size ($\eta_p^2 = 0.08$). Results are summarized in Table 2.

Mental Health Status

Table 3 provides a summary of scores for women with physical disabilities on measures that assess depression, anxiety and self-esteem. Approximately 39% of the sample of women with physical disabilities met criteria for at least moderate depression over the past two weeks in comparison to 30% of those without disabilities (overall score > 17); and 11% (vs. 6.4% for those without disabilities) meeting criteria for significant depression (overall score > 31) according to the BDI-II (Beck, Steer, & Brown, 1996). In terms of anxiety, 20% of the sample met criteria for ‘severe’ anxiety in comparison to 15% of those without disabilities (overall score > 26) over the past two weeks according to the BAI criteria (Beck & Steer, 1990).

Hypothesis 1 (continued). In comparison to the control group (M = 12.96, SD = 12.62), women with physical disabilities reported higher anxiety scores (M = 16.44, SD = 11.26), with a small effect size ($\eta_p^2 = 0.02$). No differences were found between the two groups in terms of depression scores and self-esteem (See Table 3).

Predictors of Disordered Eating, Body Dissatisfaction and Mental Health Status

Hypothesis 2. To investigate how disability impacts disordered eating and mental health, objective disability rating (RDRS), subjective disability rating, and overall health ranking for the past 30 days were entered into a series of linear regression analyses as predictors of disordered eating (RRS, EDEQ, GBES), anxiety (BAI), depression (BDI-II), self-esteem (RSES), and body esteem (BES). The full statistical summary can be found in Table 4. The predictors that achieved statistical significance included the ranking of health status and subjective disability. Objective disability only predicted one outcome. Independent contributions of each predictor were examined through partial regression coefficients. In the regression results, health status was a significant predictor of disordered eating ($\beta = -0.19$, $p = 0.03$), binge eating ($\beta = -0.18$, $p = 0.03$), restrained eating ($\beta = -0.26$, $p = 0.01$), self-esteem ($\beta = 0.33$, $p = 0.001$), anxiety ($\beta = -0.36$, $p < 0.001$), and depression ($\beta = -0.26$, $p = 0.01$). Lower health ranking was significantly associated with increased disordered eating, binge eating and dietary restraint, lower self-esteem, and greater symptoms of anxiety and depression. Next, subjective ranking of disability was a significant predictor of depression ($\beta = 0.22$, $p = 0.03$), body dissatisfaction ($\beta = -0.33$, $p = 0.002$) and self-esteem ($\beta = -0.45$, $p < 0.001$). Greater ranking of disability was significantly associated with increased depression as well as decreased body and self-esteem. Finally, higher objective disability scores (RDRS) also significantly predicted increased self-esteem ($\beta = 0.20$, $p = 0.02$).

In order to investigate the impact of number of years disabled on the dependent measures, comparisons were made between those women with acquired and congenital disabilities. A one-way ANOVA was conducted. Women with congenital disabilities reported significantly better health in the past 30 days ($p < 0.001$, $\eta_p^2 = 0.26$), lower anxiety ($p = 0.033$, $\eta_p^2 = 0.04$) and higher objective disability as measured by RDRS ($p = 0.030$, $\eta_p^2 = 0.06$). However, with the modified alpha of 0.030, the differences in anxiety scores (BAI) and objective disability severity (RDRS) between women with acquired and congenital disabilities did not meet significance. No significant differences were found in any other dependent measures (i.e., RRS, EDEQ, GBES, BES, RSES, BDI-II, BAI, subjective disability rating). Table 5 displays the means between acquired and congenital disabilities.

In addition, a series of linear regression analyses were conducted with number of years living with a disability as the predictor (Table 6). Number of years living with a disability predicted depression ($\beta = -0.29$, $p = 0.003$), anxiety ($\beta = -0.36$, $p < 0.001$), self-esteem ($\beta = 0.25$, $p = 0.008$), and overall subjective health rankings ($\beta = 0.33$, $p < 0.001$). More years living with a physical disability was significantly associated with lower depression and anxiety, higher self-esteem, and higher perceived health. Body esteem (BES), disordered eating (RRS, EDEQ, GBES) and disability severity (RDRS and subjective rankings) were not associated with number of years living with a disability.

Hypothesis 3. Past literature has suggested that body dissatisfaction is an important predictor of disordered eating in young women. To investigate this in the sample of women with physical disabilities, a series of linear regression analyses were conducted inputting body dissatisfaction as predictors of disordered eating and mental health, while controlling for BMI as a covariate. The findings were compiled in Table 7. Body Esteem (BES) was significantly

associated with disordered eating as measured by the EDE-Q ($\beta = -0.48$, $p < 0.001$), binge eating ($\beta = -0.41$, $p < 0.001$), dietary restraint ($\beta = -0.34$, $p < 0.001$), depression ($\beta = -0.57$, $p < 0.001$), anxiety ($\beta = -0.42$, $p < 0.001$), and self-esteem ($\beta = 0.69$, $p < 0.001$). Higher body dissatisfaction (low body esteem) was significantly associated with greater disordered eating, binge eating and dietary restraint. Higher body dissatisfaction was also significantly associated with greater levels of anxiety and depression symptoms and lower self-esteem.

Study 1 Discussion

The primary goal of Study 1 was to ascertain the potential risk for disordered eating in women with physical disabilities. Analyses compared disordered eating, body dissatisfaction, and mental health outcomes between women with and without physical disabilities. Further analyses examined the role of disability severity on disordered eating outcomes. Results indicated that physically disabled women were equally likely to experience disordered eating symptoms and more likely to report body dissatisfaction, poor perceived health over the past ten days, and greater symptoms of anxiety in comparison to women without physical disabilities. Presence of greater health problems and body dissatisfaction predicted increased disordered eating symptoms, whereas health problems, less time living with a disability, and feeling more disabled across different aspects of one's life predicted greater mental health problems and low self- and body-esteem. Unexpectedly, greater functional disability correlated only with increased self-esteem. Implications related to vulnerability and risk to disordered eating as well as clinical identification and manifestation differences will be explored below.

The hypothesis that women with physical disabilities would be significantly more likely to report disordered eating symptoms in comparison to women without disabilities was unsupported. Disabled women were in fact equally likely to report symptoms of disordered eating. Approximately 15% of disabled women scored above the EAT-26 screening cut-off indicative of a possible eating disorder. Although it's difficult to directly compare studies due to the use of different assessment measures and the lack of diagnostic confirmation, this number is higher than results of other studies of disabled women, which reported estimates of 8% (Gross, Ireys & Kinsman, 2000), and also in comparison to prevalence rates of full-syndrome eating disorders in general (1-3.5%: APA, 2000). This discrepancy could reflect a possible

underutilization of service for women with disabilities. Although there are no known statistics or studies to date on eating disorder or even obesity treatment in adults with physical disabilities, the underutilization of preventative healthcare services (e.g., cancer screenings) in this population has been well documented (Chevarley et al., 2006).

This study is unique in its analyses of specific disordered eating behaviour. Similar to rates in nondisabled women in the study, around 5% of participants regularly used purging methods (e.g., vomiting, laxative and diuretic abuse) to manage shape/weight. Further, it is known that the co-occurring presence of an eating disorder and a physical disability can exacerbate the health risks associated with both disorders (Valli & Walkup, 1998; Webb, Morgan, & Lacey, 2009). The current study offers further information regarding which disordered symptoms could be contributing to increased health risks for women who have comorbid diagnoses. An additional notable finding in Study 1 was that 19% of women with physical disabilities endorsed engaging in hard exercise regularly to manage their weight. Past studies to date have highlighted the low participation and the multifaceted challenges of regular physical activity for persons with disabilities (Crompton, 2011; Fox, Witten, & Lullo, 2014; Sit et al., 2007); however, results from Study 1 also highlight the need for further research on those disabled women who are engaging in exercise, particularly for the purposes of weight loss/management. It is unclear the exact frequency, severity and type of exercises that these women are engaging in or whether or not their exercise behaviours could be considered unhealthy and/or unsafe. Furthermore, these exercise behaviours would likely differ according to the type of disability and its associated mobility challenges. It is possible that the disabled women who endorsed ‘hard’ exercise are engaging in physical activity outside of clinically sanctioned health programs or other public spaces (e.g., gyms) due to issues around

environmental inaccessibility, financial constraints, and other barriers that prevent women from exercise in public spaces (Dwyer, Allison, Goldenberg, Fein, Yoshida, & Boutilier, 2006; Malone, Barfield, & Brasher, 2012). Most past research has been conducted from an obesity and health promotion perspective and the current study is novel in its examination of exercise in the context of disordered eating and possible over-exercise.

The current study is the first to examine binge eating behaviour specifically in a sample of physically disabled women. In the current study, approximately 29% of disabled women reported that they engaged in regular binge eating (at least once per month), meaning that they endorsed eating an objectively large amount of food over a short period of time and experienced feelings of loss of control. These rates are higher than those of one Canadian study that estimates 13.7% of Canadian women binge eat at subclinical levels (Gauvin, Steiger, & Brodeur, 2009). However, in comparison to the control sample of nondisabled university students, disabled women actually engaged in slightly less binge eating behaviours (5% less). Although still clinically relevant, it may be that physically disabled women experience unique risk factors for binge eating in comparison to those without disabilities. Previous research on eating in persons with disabilities has suggested links between the experience of disability-related stress/distress and overeating (Pells et al., 2008), disordered eating (Siler, Shaer, & Atkins, 1999; Webb, Morgan, & Lacey, 2009), and other mental health issues (Turner & McLean, 1989) in persons with disabilities. There also may be aspects of physical disability that protect an individual against binge eating. For instance, it is known that disabled persons experience greater poverty and health issues that could impact one's ability to engage in binge eating. More research is needed to understand other possible connections deemed important in binge eating literature, such as body dissatisfaction and attachment for disabled women.

Although participants were equally likely as their nondisabled peers to report symptoms of disordered eating as measured by the EDEQ, RRS and GBES, disabled women were overall less satisfied with their bodies in terms of its weight and shape as well as functionality or physical condition. These findings were consistent with other studies conducted on disabled women (Gross, Ireys, & Kinsman, 2000; Taleporos & McCabe 2005), including those with multiple sclerosis (Samonds & Cammermeyer, 1989), arthritis (Gutweniger et al., 1999), and spinal cord injury (Moin, Duvdevany, & Mazor, 2009). Even though disabled women in the current study felt worse about their bodies, this did, at least not directly, translate to increased risk for disordered eating in comparison to women without physical disabilities. An important distinction should be made between body dissatisfaction related to weight concern and that from physical condition. Follow up analyses on how body dissatisfaction predicts disordered eating and mental health symptoms (Hypothesis 3) found that weight concern was significantly associated with disordered eating while physical condition was only associated with mental health symptoms. Therefore, it is possible that the increased severity of body dissatisfaction in the disabled women in this sample was exaggerated somewhat by the confounding impact of physical condition/health problems on body dissatisfaction measures. Disabled women may also be coping with or responding to feelings of body dissatisfaction differently from women without disabilities. For instance, whereas there is no readily apparent solution to body dissatisfaction related to physical disability, for women who struggle to accept their weight and shape, dieting with the intention of losing weight can be viewed as a method for bodily acceptance. Research on the positive impacts of coping with body dissatisfaction in women with spinal cord injuries corroborates the possibility that acceptance of physical condition

enhances body satisfaction with time (Baily, Gammage, van Injen, & Ditor, 2015; Basset et al., 2009).

Some scholars have suggested that disabled women are not dissatisfied with their bodies in the same way that women with eating disorders are believed to have a distorted view of their shape and weight (Gross, Ireys, & Kinsman, 2000). Women with eating disorders typically believe that they are fatter or more unattractive than they actually are, whereas physically disabled women's body image may be an accurate interpretation of their "attractiveness," as it is represented in a society that devalues disability. The majority of current research on the impact of body image on disordered eating has been produced on young women with eating disorders. Less is known about how body dissatisfaction fueled by an accurate interpretation of a sociocultural preference for nondisabled bodies may impact a woman's risk for disordered eating and other mental health issues. It may be that body dissatisfaction for disabled women is unique and associated with different risks than the body dissatisfaction generally related to weight and shape concerns commonly studied in women without disabilities.

In terms of mental health outcomes, the only significant difference found in the current study was that women with physical disabilities reported higher levels of anxiety than nondisabled women. Given the considerable research on the increased rates of depression in persons with disabilities, the current results are somewhat surprising and may reflect characteristics of the current sample (e.g., relatively young age, high socioeconomic status, high prevalence of those with congenital disabilities). Consistent with the findings of Brenes and colleges (2008), the current findings affirm the need for further research and clinical attention to anxiety in persons with physical disabilities. Like depression, anxiety symptoms can negatively impact health and quality of life of those with disabilities (Brenes et al., 2008).

Although it is unclear what factors specifically contributed to greater anxiety in the current sample of disabled women, previous research has suggested that there are a few potential factors associated with disability that could contribute to increased anxiety. For one, living with a physical disability often involves numerous and uncontrollable stressors, such as depending on different caregivers and navigating inaccessible systems and physical environments (Nosek, Hughes, & Robinson-Whelen, 2008). Second, uncertainty in relationships can be common for disabled persons due to negative societal attitudes related to disability, which may contribute to symptoms of social anxiety in the disabled individual (Oberlander, Schneier, & Liebowitz, 1994). Third, physical disability is frequently affiliated with increased health problems, such as chronic pain, unpredictable functional limitations, fatigue, and general illnesses (Holmes, O'Donnell, Williamson, Hogg, & Arnold, 2014). In each of these three situations (i.e., stress, social, health), there are increased likelihood of experiencing uncertainty and unpredictability, which in turn could lead to greater anxiety.

There are certain disability characteristics and psychological factors not examined in the current study that could offer additional clarification on the relationship between health problems/physical disability and elevated anxiety. Illness uncertainty has garnered attention in the study of anxiety as well as the health and well-being of those with physical disabilities. For instance, in one study, it was a significant predictor of eating disorder symptoms in disabled women (Gross, Ireys, & Kinsman, 2000). Illness uncertainty refers to the inability to determine the meaning in illness related events (Mischel, 1988). High levels of uncertainty, a component in all chronic illnesses and particularly those with a high degree of symptoms and secondary health conditions, are related to high emotional distress, anxiety, and depression (McCormick, 2002). Further, increased anxiety and illness uncertainty may also impact health-related self-

efficacy. Studies have shown that self-efficacy is also related to positive health outcomes (Clark & Dodge, 1999) as well as active health management (Perry, Nicholas, & Middleton, 2009) in persons with physical disabilities. Interestingly, high self-efficacy has also been linked to resisting eating in obese persons with arthritis (Pells et al., 2008). Taken together, not only can health problems feel unpredictable and overwhelming, but they can also contribute to an erosion of an individual's belief and self-confidence that they can successfully negotiate those changes in health and related problems. More research is warranted in further understanding potential etiological mechanisms of anxiety and physical disability.

Greater reported health problems was the only measurement of disability that significantly predicted disordered eating symptoms. The findings are consistent with those reported in qualitative studies. In Silber, Shaer and Atkins (1999), participants with spina bifida and an eating disorder reported that their eating disorder was partially attributable to a need to manage the stress and chaos associated with their lives as disabled women. The authors further discussed how women's alignment with an eating disorder allowed them to escape the "despair related to their spina bifida" (pg. 5). In another study, the presence of multiple medical conditions was significantly associated with symptoms of eating disorders in women with physical disabilities (Gross, Ireys, & Kinsman, 2000). These findings in Study 1 also provide clarification on past research that found a correlation between prior physical illness and the development of an eating disorder (e.g., Neumark-Stzainer et al., 1995; Watkins, Sutton, & Lask, 2001). It seems that it was not physical disability per se that contributed to increased risk for disordered eating, but rather the experience of health problems. As discussed above, disordered eating behaviours could be understood as a response to increased stress, decreased

sense of control and predictability, and mental distress associated with health problems among women with physical disabilities.

The use of differing operationalizations of disability, in the analyses of disordered eating and mental health in this dissertation, constitutes a unique contribution. The study measured and compared subjective feelings of disability, objective measures of disability (i.e., functional limitations), and self-reported health ranking. Results indicated that an individual's health ranking was the construct that correlated most strongly with psychosocial outcomes, followed next by subjective feelings of disability. Interestingly, so-called objective measures of disability, such as how far a person can walk or how long a person can remain standing was not predictive of any psychosocial measures besides self-esteem. This was also true of all other measures of functional disability in the current study, even those that were not reported (e.g., needing of assistance, level of impact a woman's disability had on her physical appearance). This is consistent with growing literature reporting that disability characteristics (e.g., severity, age of diagnosis, visibility) have limited predictability of psychosocial outcomes (e.g., Groarke, Curtis, Coughlan, & Gsel, 2004). These findings in Study 1 call to question the widespread use of functional measures of disability exclusively in medical and rehabilitation settings as predictors of quality of life and well-being.

This study also highlighted an important differentiation between persons with congenital and acquired physical disabilities. Participants with acquired disabilities were much more likely to report symptoms of anxiety. Furthermore, these women reported significantly worse health ratings over the past ten days, which probably contributed to the higher anxiety. These findings are in contrast to previous research that has reported poorer psychosocial outcomes for those with congenital disabilities, due to limited socialization and community involvement

(Campbell, 1995; Hopper, 1984; Sheriff, 2004). However, in the current study, all of the women were young adults who had had more time to cope with their physical disability as opposed to the younger population of children and adolescents examined in the studies cited above. Further, as previously mentioned, much of the previous research comparing congenital with acquired disabilities failed to differentiate between functional, subjective and perceived health. As a result, lower reported quality of life outcomes examined in past research are probably inflated because of poorer functional disability ranking. In other words, the lowest quality of life is commonly assumed with more severe functional disability; however, research findings on life satisfaction with a disability do not support this relationship. In fact, these inherent assumptions in the study of quality of life are often more informed by societal perceptions of disability than that of empirical research.

In Study 1, the young women with acquired disabilities had lived an average of 15 fewer years with their physical disability than had women with congenital disabilities. Not surprisingly, the current study uncovered a relationship between the greater number of years a participant has been living with their disability and absence of health and mental health problems as well as increased self-esteem. Overall, more time living with a disability leads to *better* health and mental health outcomes. In relation to the current study, past research of disabled women has also corroborated findings that over time, symptoms of disordered eating and body dissatisfaction show a significant reduction (Pinquart, 2013). The literature on coping with disability offers some potential explanations. Most longitudinal studies find that persons newly diagnosed with a disease or physical disability initially react with higher psychosocial distress that eventually dissipates over time (Kovacs et al., 1995). Further, another study found that the use of coping strategies (e.g., positive reframing, emotional support, acceptance) added

significant variance between disability-specific conditions (e.g., functional limitations, visibility of condition) and psychosocial adjustment (Livneh & Wilson, 2003). Although specific definitions of coping can vary across studies, some consistent examples of coping can include development of positive social support or community (Jensen, Smith, Bombardier, Yorkston, Miro, & Molton, 2014), psychological resiliency (Martz & Livneh, 2016), and increased self-efficacy (Rigby, Thornton, & Young, 2008).

Taken together, Study 1 offers some initial conclusions as to who, within the community of physically disabled women, may be most at risk for developing disordered eating symptoms. First, as previously discussed, women who have recently acquired their physical disability, those reporting health problems, and those reporting multiple negative impacts of their physical disability seem to be the most risk for developing disordered eating symptoms. Second, within the population of disabled women, those who reported higher body dissatisfaction were more likely to also endorse disordered eating and other mental health problems. As previously discussed, in comparison to women without disabilities, the elevated body dissatisfaction scores in disabled women did not directly translate to elevated disordered eating scores. However, within the population of disabled women, body dissatisfaction related to weight/shape was a significant predictor of disordered eating. This finding is consistent with well-established research linking body dissatisfaction with eating disorders (Polivy & Herman, 2002). Further, this finding is consistent with qualitative studies done with disabled women who report that early efforts to restrict dietary intake were motivated by body dissatisfaction and attempts to lose weight (Silber, Shaer, & Atkins, 1999; Watson, 1999; Webb, Morgan, & Lacey, 2009). More research is needed that can tease apart the meaning of body dissatisfaction within a disabled population. For example, perhaps only body dissatisfaction related to weight

and shape predicts disordered eating, whereas dissatisfaction related to appearance and functionality are less insidious with regards to mental health and disordered eating.

Limitations and Subsequent Research Questions

Study 1's results have highlighted a number of limitations in terms of using a survey-based, quantitative methodology with the population of adults with physical disabilities. First of all, the disordered eating scales were not validated for a disabled population. Many of the women wrote within the open comments section of the survey that they could not fill out certain questions or that they felt the scale did not accurately represent their specific situation. For example, women who used G-tubes or had difficulty swallowing certain foods may seem 'disordered' in their eating due to complex medical needs and avoidance of specific foods. Second, measurement of Body Mass Index (BMI) was flawed within this population. Many women reported that they did not know their weight or height due to difficulties in finding accessible weight scales. Previous research has also called into question the use of BMI on persons with physical disabilities (see Fox, Witten, & Lullo, 2014 for a review). The review highlighted a number of issues, including the fact that self-reported BMI was more inaccurate in this population; height and weight, when they were obtained, could often not be accurately measured; and persons with physical disabilities often differ in body composition in comparison to those without disabilities. Future studies are advised to use alternate methods of measuring weight (e.g., waist circumference), particularly as it relates to health and fitness. Third, measuring the psychosocial and physical impact of a woman's disability was challenging. There are multiple ways to conceptualize disability and health, indeed there are numerous, and sometimes conflicting, views on what disability and health means for a person and within society. Given this complexity, it was impossible to capture the personal impact of an

individual's disability and their health using quantitative-based scales. Further, defining disability in a narrow manner (i.e., as those with physical/mobility disabilities) led to restrictions regarding who to include within the study (e.g., participants who are blind, deaf, have cancer, etc. were excluded). Lastly, the sample of women with disabilities used in our sample may not be representative of the general population of disabled persons in Canada. Our sample had a high education status. Interestingly, the samples were matched between reported annual income. It's possible that despite having higher education status, our sample of disabled women were not achieving employment and income rates expected, further suggesting that barriers to employment for this population remain rampant.

The findings in Study 1 have also provided some new research questions and potential avenues for future study regarding the phenomenon of disordered eating in women with physical disabilities. For one, questions remain as to how disordered eating manifests in women with disabilities. Although there may have been some validity issues with the disordered eating scales, physically disabled women still clearly reported, even within the comments section, difficulties with restriction, purging, over-exercise, binge eating, and fear of weight gain. Further, it is uncertain whether or not these scales could have either under- or over-represented the prevalence of disordered eating within this sample. Secondly, there remains some confusion with regards to the meaning of body dissatisfaction in the sample of women with disabilities. According to the Transdiagnostic Model of eating disorders, body dissatisfaction is a core feature of disordered eating (Fairburn et al., 2009); however, for women with disabilities, elevated body dissatisfaction did not lead to elevated disordered eating scores. The findings in Study 1 could allude to different definitions of body dissatisfaction, some of which may increase one's risk for disordered eating (e.g., dissatisfaction with weight) more so than others

(e.g., dissatisfaction with functionality). Although women reported that they were dissatisfied with their bodies, it is not clear how this may or may not translate towards risk for disordered eating. Furthermore, if these women are more dissatisfied with their bodies but aren't at a higher risk for disordered eating, are they utilizing coping skills or other protective factors unique to disabled women?

Next, more information is needed with regards to how health problems, frequently found in persons with newly acquired disabilities, contribute to disordered eating and other mental health issues. The findings seem to suggest that greater stress of health-related problems, possibly exacerbated by a high illness uncertainty and low self-efficacy, combined with limited time to develop appropriate coping strategies for living adaptively with a physical disability, can leave a woman at high risk for experiencing mental health difficulties as well as disordered eating symptoms. However, the specific reasons as to why persons who have lived with their physical disabilities longer also report fewer or less severe health problems fare better psychosocially remain unknown. For instance, it is uncertain whether persons living with their disability longer experience less health problems or whether their perception and interpretations of health issues becomes less negative. More research is needed with regards to how disordered eating and body dissatisfaction might change with increased age and the advancement of age-related health problems. Also, if persons with physical disabilities are less likely to struggle with disordered eating and body dissatisfaction with time, what specific protective factors may be at play? What does coping well with a physical disability mean in the sense that it protects the individual from disordered eating and mental health issues? Some of these questions and limitations in Study 1 will be explored further in Study 2.

STUDY 2

Qualitative Research Objectives

Specific objectives of the Study 2 are as follows:

1. To more fully understand the phenomenon of disordered eating in women with physical disabilities. Specifically to inquire about how disabled women experience eating and their bodies as well as how participants perceive that their experiences differ and/or match those of women without physical disabilities.
2. To inquire further into the meaning and validity of the findings of Study 1 as well as the participants' experiences in filling out the surveys. Sample questions include how women felt the survey questions did and/or did not represent their experiences with eating, disordered eating, mental health and body image.
3. Given that both the previous literature and Study 1's findings have highlighted equal-to-increased risk for disordered eating in women with disabilities, yet there is no known research and clinical writings around use of support and treatment, an important objective of Study 2 was to identify any potential barriers to healthy living and/or treatment for disordered eating for disabled women.

Theoretical Framework

A critical disability studies framework (Oliver, 1990) was adopted in the present study, specifically Thomas's (1999) social relational model of disability described earlier. Given that most of the assumptions of disordered eating have been based on that of able-bodied females, this study aimed to ascertain whether or not these disordered eating behaviours are, in fact, representative of a disabled-bodied population. The study allows for participants themselves to explore how their eating may relate to their physical disability.

The study utilized the grounded theory method (GTM: Glaser & Strauss, 1967) as modified for psychological inquiry by Rennie, Phillips and Quartaro (1988). Given the lack of literature and theory in the area of disordered eating for women with disabilities, this discovery-oriented approach to enquiry was deemed suitable. This approach allows for in-depth study, leading to a holistic understanding of complex phenomenon (Rennie, 1998).

Method

Methodology

Within the GTM, methodical hermeneutics was chosen as the methodology to inform the present study and analyses. These modifications of the GTM by Rennie (2010) allows the researcher to hold some a priori assumptions about the phenomena and provides guidelines as to how to bracket these assumptions, while still encouraging open-ended inquiry. In this method, the interpretation of text is conceptualized within the context of the hermeneutic circle (Dilthey, 1996b). Here, the researcher engages in the activity of educing meaning from the transcript while simultaneously participating in processes of abduction, deduction and induction. Eduction refers to a process in which the researcher draws forth meaning from the text based on a vague embodied felt-sense. Then processes of abduction, deduction and induction are used in a cyclical fashion and are continuously informing the interpretation of the text as a whole. In other words, the researcher engages in a continual process of proposing tentative interpretations in relation to his or her understanding of the interview data, attaching meaning to those interpretations through the development of theoretical categories, and searching for evidence in support of those theoretical concepts in an iterative fashion (Rennie, 2010).

Situating Oneself as the Researcher

An important aspect of qualitative research is understanding how the researcher's experiences shape and influence the qualitative research process. Further, because this research is situated in a critical disability studies framework, participation of disabled researchers is not only recommended, but necessary. My interest in this topic was most definitely impacted by my identity as a woman with a physical disability. It is through this lens that I experience all aspects of my life. Some lenses I embody out of necessity. Navigating the world in a wheelchair, I am constantly on the look out for ramps, elevators, curb cuts, and automatic doors. The white and blue wheelchair symbol that people often associate with disability stigma, for me, represents freedom and inclusion. Other lenses, I recognize, have grown out of my ongoing incorporation of what it means to be a disabled person with my identity. Over time, this identification has shifted from accepting a medical diagnosis and my own physical limitations to acknowledging that I am a part of a marginalized group of people in society as well as a unique community of people that exist outside of the "norm". I found myself reflecting a great deal on my own journey from being a confused and uncoordinated child, to the diagnosis of muscular dystrophy, to learning how to interact with the world from a wheelchair, and to finally (mostly) accepting and embracing my identity as a disabled woman. However, that journey was anything but linear and was characterized by rapid shifts and changes.

As a psychology student trained in applying conceptual models to complex psychological phenomenon, I found myself both relating to my participants' stories as well as classifying their experiences into a developmental model similar to my own. However, when I shared my understanding with the participants, there was almost always a complication and a

resistance. It seemed that the individual journeys that each participant faced as a person with a disability were not so straightforward and did not fit into neat stages that so many psychologists of past have developed in understanding grief and coping with illness and loss. Eventually, I had to let go of the idea that I would have a neat conceptual model that would capture all of my participant experiences and this allowed me to be more open to new understandings and new complications to the story.

When I first decided to combine my interest in working with disability with studying eating disorders, my initial feelings about my relationship to the topic were overly simplistic and uncomplicated. I had a very "black-and-white" understanding of the topic. I recall that I told my Qualitative Research Methods professor at the time that although I was also a woman with a disability, like my participants, I did not have an eating disorder and therefore, my understanding of this topic was strictly clinical and objective. I had been originally drawn to the field of studying eating disorders out of clinical interest. I wanted to work in a career that aimed to understand and treat psychological problems associated with physical health. As a feminist, I also believed strongly that assigned gender roles and the pressure for women to conform to a socially-constructed idealistic beauty standard was damaging, dangerous and had negative implications for both physical and psychological health. However, as I started to conduct interviews, I better understood the complexity that existed along the disordered eating spectrum. Most of my participants did not meet full clinical criteria of an eating disorder. Most were not the women with whom I worked clinically in an eating disorder clinic; rather, their eating behaviours were more how we would classify as normative and the women were highly functional. Further, they all struggled with issues more complex than eating less food to look

more like society's idealistic beauty standards. They were trying to lose weight so that they could reduce chronic pain or ensure that they could still manage transfers independently.

It was with this adjusted understanding that I began to notice more of my own experiences within my participants. I too had gone on strict diets, particularly while I was still in high school and there was a real perceived threat of not being able to go to university and live independently. During that time, I lost weight and former strength did return to my body. At the beginning of the study, I had classified all dieting as "bad" for women's mental health and physical health, which unintentionally could lead to more dangerous eating disordered behaviours. However, I understand better now how diverse and complex the interaction is between physical disability, eating, and body image/body satisfaction. I also have attempted to integrate more of a social-relational understanding with disordered eating and disability. Through being open to integrating my own experiences with eating to this research, I believe that I have become much more aware of how social-relational factors impact eating and body satisfaction in women in general. Although the women in my study differed, often substantially, in physical functioning, health status, psychological health status, weight/size, and cognitive abilities, they all shared a common story of coming across barriers to healthy living, support and treatment, and full inclusion into society. This is also the story that I have experienced. One that has also contributed to decisions to reduce my food intake, give up on physical exercise, avoid doctor's appointments, and so forth.

As I progressed through the interviews, I became intimately more aware of how complicated the relationship is between eating and disability. I found myself relating to much more of the material the participants were sharing than I had expected. I had strong urges to jump into the conversation with my own personal stories and engage in active meaning making

with the participant. Sometimes, I did allow myself to share stories and discuss my thoughts on a specific phenomenon. I believe that in those moments our mutual co-construction of meaning generated a rich understanding of eating with a physical disability. However, it was equally important for me to be aware of my own thoughts, feelings, and interpretations on the topic, use them as information as well as material to express empathy and understanding to the participant, and simultaneously to be able to hold back at times and allow space for new understandings to emerge. Theoretically, this process appears sound and intuitive, allowing for simultaneous rigour and attention to researcher biases in addition to the necessary fluidity and creativity to allow for new understandings to emerge. That being stated, it was challenging for me in the interview process to determine appropriate moments to "bracket" as opposed to share with the participant, as well as draw on my own experiences versus push myself to consider the individual's experience as entirely unique and novel. I found myself, as a researcher originally trained in empirical, quantitative methods, favouring the position of holding back. In some instances, this approach was beneficial in that I discovered much information that was discrepant to my own experiences. Other times, I may have missed opportunities to delve deeper into an experience and to form new understandings. Over time, I grew in confidence and did grant myself more permission to use my experiences as information. I realized quite early in the process that it would be nearly impossible for me not to draw on my own experiences. Additionally, because my disability is visible, many of the participants invited me as a co-creator or assumed that I also experienced many of the same experiences even if I did not share my own stories. I found that a helpful balance, for me, was to share with my participants, usually near the end of the interview, some of my own thoughts and interpretations to the material that they were sharing. During this time, I often compared their experiences with my

own in addition to the other participants in the study. In those moments, I felt confident in my approach because my participants would not hesitate to dismiss my interpretations or experiences and offer their own. They also would almost always add to my foundational understanding of the phenomenon in question; thereby, succeeding in my intent to offer information yet not completely shape the direction of the interview.

Data Collection

Selection and Recruitment of Participants

Eleven women with physical disabilities were recruited from the eligible participant pool from Study 1 (i.e., those who had provided permission to be contacted for additional research studies). The women were of diverse social and ethnocultural backgrounds. Women were selected for Study 2 based on elevated scores (at least one standard deviation above the mean for disabled women) on measures of disordered eating and body dissatisfaction completed in Study 1 (See Table 8 for a summary of scores). Out of 15 women invited to participate, 13 women volunteered to be interviewed. Two women were subsequently unable to participate due to scheduling difficulties. With respect to exclusion criteria, women with current significant medical problems, both related to severe eating problems and/or other health problems, were unable to participate due to health/risks. This included women who were hospitalized. Also, women whose disordered eating scores were elevated primarily because of impairments related to their disability (e.g., those who used a feeding tube) were excluded due to the potential confounding relationship. The presence of digestive issues in itself was not an exclusionary criteria, assuming that the individual endorsed additional symptoms of disordered eating and/or body dissatisfaction above that of the medically necessary need to restrict some food types and

select appropriate caloric intake. In addition, participants were required to have enough fluency in the English language to engage in a verbal interview.

Women were recruited over 13 months beginning in February of 2013. Because participation in Study 1 was online, women in Study 2 were contacted via email. Although the majority of participants resided in Toronto at the time of the study, there were three participants who were recruited from other provinces and countries, including Montreal (Canada), New York (U.S.A.), and Sydney (Australia). Participants who responded to an email invitation were informed that participating in the study would involve a single one-to-two hour interview that would explore their difficulties with eating, weight management, and body image acceptance. The study was approved by the ethics committee at York University. Participants were provided with an electronic or paper copy of the Informed Consent Form (Appendix B) outlining the limits of confidentiality, risks and benefits of participating, and the right to withdraw from the study without penalty. Following instructions to carefully review the Consent Form, participants were given the opportunity to ask questions or discuss any concerns about the study.

Recruitment criteria evolved throughout the study, as suggested by theoretical sampling guidelines outlined in Rennie, Philips and Quartaro (1988). Women were initially selected from those who consented in Study 1 based on endorsement of problematic eating behaviours (as measured by the EAT-26 and EDEQ). As new insights from the interview analyses emerged regarding the phenomenon of disordered eating with a physical disability, the criteria also changed in accordance with the principles of theoretical sampling (Rennie, Philips, & Quartaro, 1988). After selecting women with elevated scores on disordered eating scale, analyses of these women suggested the need to recruit women who acquired their disability later in life as well as

women who rated their overall health as low. Further, women with high reported anxiety symptoms, binge eating scores, and body dissatisfaction without predominant symptoms of disordered eating were targeted in later interviews. As well, women of more diverse ethnocultural backgrounds were targeted as the majority of initial interviews were done with women of Euro-Canadian descent. Similarly, women with more diverse body types (e.g., those with very high or low BMIs) were recruited to widen the scope of exploration with regards to problematic eating. Below, in the *Participants* section, the reasons for selecting each participant are described in more detail.

Interview Process

The interview lengths ranged from 55 to 122 minutes. All interviews were conducted in a quiet, private room either at York University or in another suitable location of the participant's choosing. Women who could not be physically present for the interview due to difficulties with travel or geographical distance met with the interviewer over Skype; software that allows for online conference meetings. All interviews were recorded using a digital recorder. Participants were asked to pick a pseudonym that was used in the recording, storage and dissemination of the interview data to protect their anonymity throughout the research process.

The interview consisted of open-ended questions related to their experiences with eating, weight management, and body acceptance. All interviews were conducted by myself, the primary researcher. A list of sample interview questions (Appendix D) was used to guide the interview; however, I followed the discussion that emerged from the participants in order to allow for new understandings to emerge as well as a greater breadth of their experiences. Following the interview, I recorded some of my initial thoughts in the form of a memo. In the

memo, I described the interview content and process, any notable affect in either myself or the participant, and some preliminary interpretations with regards to her interview material. In these early memos, I tended to write uninhibited and allowed myself to form initial opinions or suspected relationships between different interviews as well as among emergent themes. Later, the recordings were transcribed, word-for-word, by trained volunteers.

Participants

A total of eleven women participated in the study. The number of interviews was determined when the data became saturated and no further categories were deemed necessary to account for the meanings or themes apparent in additional transcribed interviews (Glaser & Straus, 1967). In the present study, no new themes emerged following the analysis of the ninth interview. As previously mentioned, recruitment criteria changed as the ongoing analyses uncovered new areas of inquiry to explore. Toward the end of the recruitment, I attempted to interview a women who identified she had been in a treatment facility for eating disorders; however, after multiple attempts to meet, we were unable to complete the interview.

In terms of demographic information, the majority of women identified as Caucasian/European descent. One woman identified as first-generation African and another identified as first-generation Middle-Eastern cultural background. Although all participants spoke fluent English, there was one participant who primarily identified as Francophone and needed occasional assistance describing her experiences in English during the interview. Schooling experiences included mainstream public or Catholic school as well as some specialized schooling for persons with disabilities in primary school. All of the participants reported being integrated with mainstream schooling, with varying degrees of assistance from teaching assistants (from none to full assistance). In terms of education level, the women ranged

from the partial completion of a college/university degree to a graduate degree. The socioeconomic status ranged from working-class to middle-upper class. Two of the participants were married and four were in a long-term relationship at the time of the interview. All the women identified as heterosexual. In terms of disability status, the women differed in terms of having an acquired or congenital disability across diverse levels of functioning. Most of the participants used a wheelchair or walker as their primary mobility device. Three of the participants reported having past diagnoses of an eating disorder. All of the participants identified that they had problems with eating (e.g., overeating, dieting, purging, binge eating) or with managing their weight. Body Mass Index (kg/m^2) was recorded for each participant based on self-reported height and weight, if known. Classification for weight status (i.e., underweight, normal weight, overweight, obese) was based on the International Classification of adult underweight, overweight and obesity based on World Health Organization (WHO) recommendations (WHO, 1995). The following provides some background information on each of the participants who were interviewed. Pseudonyms were used to identify participants.

Kendra

Kendra is a 29-year-old single woman of Euro-Canadian descent who lives in an apartment alone in Toronto, Ontario. She is pursuing a doctoral degree in Equity Studies and works full-time for a non-for-profit disability-related organization. Kendra identified her socioeconomic status as middle. She reported that she is casually dating men that she meets online. Kendra was diagnosed with cerebral palsy at birth. She has used a manual wheelchair as her primary mobility aid for all of her life. Kendra can walk short distances and stands with support of a grab bar for her transfers. She does not use personal support workers for activities

of daily living or food preparation. She denied that her disability directly impacts her ability to metabolize food. She rated her disability severity as moderate.

Kendra grew up with her parents and twin-sister who also has cerebral palsy and uses a wheelchair. She recalled that her parents also encouraged her and her sister to participate in sports-related activities. Her mother worked as a diet consultant and promoted healthy eating. Kendra reported that there was always an emphasis in her household on portion control and weight-loss. Subsequently, Kendra reported that once she lived on her own, she started engaging in regular binge eating. She also recalled that she would eat so much food that she would purge by vomiting.

Kendra's Study 1 survey results revealed that she had high levels of body dissatisfaction, restrained eating and disordered eating behaviours, including purging behaviour. She also endorsed a very high level of anxiety on the BAI scale. Kendra's current self-reported BMI would suggest that she is overweight. Kendra believes that she needs to lose about 30 pounds of weight. She has had pressure to lose weight at different times in her life from both health care professionals and family members. She currently follows a low-carb diet ("paleo") and exercises at the gym regularly. Kendra has never received mental health treatment for her eating. She has received health advice from her private trainer at her local gym, which is where she received recommendation to go on a low carb diet.

Michelle

Michelle is a 29-year-old single woman of Euro-Canadian descent who lives alone in a community integrated supportive housing unit in Toronto, Ontario. She has some college education. Michelle works occasionally as a freelance writer. She is looking for full-time work that will be accommodating for her disability and currently collects disability income supports.

Michelle identified her socioeconomic status as low. Michelle was diagnosed with cerebral palsy (CP) at birth. She rated her disability status as moderate. She uses an electric wheelchair as her primary mobility aid. Michelle relies on attendant services for all activities of daily living and food preparation, which she has 24-hour prescheduled access. She can bear weight for brief periods of time and stands up with assistance for all her transfers. In terms of food preparation, she can eat independently if the food has been prepared and cut for her in advance. Michelle reported that her CP makes it difficult for her to put on weight. She also reported that she uses laxatives because of digestive issues that are common for people with CP.

Michelle recalled that she first went on a restrictive diet at the age of 13. At that time, she recalled that her mother was initially supportive and helped her follow a diet-plan. However, over time, her mother urged her to receive treatment when Michelle's restriction became extreme and she lost a significant amount of weight. Michelle was diagnosed with anorexia nervosa at the age of 27; however, she noted that she first restricted to the point of amenorrhea at the age of 15. She considers herself to be recovered, although admits that she still struggles with urges to restrict her food intake. She reported that she feels pressure to lose weight so that she is easier to transfer for the attendants who assist her; however, she knows that she needs to maintain or possibly gain weight. Michelle explained that her feeding and digestion issues associated with having CP contributed to the delay in her subsequent diagnosis of AN.

Michelle's Study 1 survey results found that she had high levels of disordered eating, binge eating, and restrained eating behaviours. Michelle was chosen to be interviewed because of her elevated scores as well as her endorsement of having a diagnosed eating disorder in the past. Michelle's BMI is 17, which classifies her as underweight; however, she believes that she

is maintaining a healthy BMI and noted that she has maintained this BMI over the past year. Michelle attends private psychotherapy for her eating disorder management on a weekly basis.

Carrie

Carrie is a 24-year-old single woman of Euro-Canadian descent. She lives alone in a community-integrated supportive housing apartment. Carrie is currently pursuing a Master's degree in social work and receives disability income supports. She identified her socioeconomic status as middle. Carrie was born with an unknown type of neuromuscular disorder. She has used an electric wheelchair as her primary form of mobility throughout her life. Carrie can walk short distances with support and stands briefly for her transfers. She uses attendant services for assistance in activities of daily living and meal preparation. Although she has no difficulties eating independently, she requires assistance for purchasing and preparing food.

Carrie was raised in a home with her parents, who emigrated from Italy before her birth, and her two older sisters. She recalled that she first started worrying about her appearance in middle school. She reported that she engaged in dieting behaviour since that time. Carrie reported that she has been advised to lose weight by health care professionals, attendant support workers, and family members. Carrie discussed in her interview how she frequently overeats then tries to manage her weight using diet and/or exercise.

In terms of her survey results, she endorsed high levels of binge eating and disordered eating behaviours. Carrie's BMI would suggest that she is overweight. Carrie believes that she needs to lose 15 pounds to improve her appearance and her health. Carrie elaborated that she was advised to lose weight to help decrease her scoliosis and back pain as well as improve her breathing and ease of transfers. She has never received mental health supports for her

disordered eating. Carrie reported that she had seen a dietician and has attended a gym/exercise class developed for persons with disabilities in the past.

Amy

Amy is a 32-year-old woman of Euro-Canadian descent who lives with her husband in an apartment in Toronto. Amy and her husband use 24-hour attendant services that reside in her community-integrated supportive housing apartment for activities of daily living. Amy has a Master's degree and works full-time as a disability services counsellor at a college. She identified her socioeconomic status as middle. Amy was diagnosed with Arthrogryposis, a neuromuscular disorder, at the age of two, which is a progressive muscle weakening disease that impacts her skeletal muscles. She has used an electric wheelchair all her life. Amy cannot bear any weight and uses a hoist for her transfers. Her muscle weakening disease also hinders her ability to breathe. She uses a continuous positive airway pressure (CPAP) machine at night to assist with breathing. Amy reported that when she eats too much food, her breathing becomes increasingly compromised. Amy rated her disability severity as severe. She needs full assistance for transfers and moderate assistance for meal preparation and eating.

Amy grew up with her mother and younger sister in a home in Toronto. Amy recalled that she has had challenges with her weight her entire life. She explained that her doctor frequently recommended that Amy lose weight since she was twelve years old. She reported that she used to become extremely anxious prior to any of her appointments because she did not lose weight as was expected. This would trigger her to fast for a few days prior to the appointment in the hopes of losing some weight. Amy reported that today, she still struggles with her weight; however, she has become more accepting of her weight and satisfied with her appearance.

Amy's survey results found that she had high levels of binge eating behaviour as well as high symptoms of anxiety. Her self-reported weight is 185 pounds. She was uncertain as to her height, therefore BMI could not be calculated. As mentioned, Amy had been advised by both medical professionals and caregivers that she should lose weight. She hopes to lose 50 pounds to improve her health and her breathing ability. Amy has never seen any healthcare professional for her eating or weight management with the exception of her primary-care physician.

Jess

Jess is a 21-year-old single female of African-Canadian descent who was pursuing full-time studies at university at the time of the interview. She reported that she is not interested in dating because she does not feel 'confident' enough. Jess identified her socioeconomic status as low at the present time. She immigrated to Canada from Nigeria as a teenager following a motor vehicle accident. Jess endured serious injuries to her knees, hips and back following the accident that occurred when she was twelve-years-old. Jess currently uses a cane to walk and has been diagnosed with osteoarthritis due to her injuries. Jess also suffers from chronic pain on a daily basis that negatively impacts her productivity and her overall quality of life.

In terms of her eating history, Jess reported that since her accident occurred, she has been engaging in disordered eating behaviours in an effort to lose weight. Jess reported that she has a history of extremely restrictive dieting where she would eat nothing for days at a time. She reported that this would sometimes result in symptoms of dizziness or lightheadedness. One time, she was taken to the hospital because of severe dehydration. Jess reported that she does not engage in extreme restrictions anymore due to health risks; however, she always tries to limit her caloric intake. Jess reported that she often engages in binge eating behaviours after a period of dieting. Her binge eating contributes to feelings of guilt and shame, particularly

given that extra weight exacerbates her chronic pain issues. Jess rated her disability severity as moderate, although she noted that the impact on her can vary on a daily basis depending on her level of chronic pain or injury. She further reported that she does not require any assistance for transfers, meal preparation, or eating.

Jess's Study 1 survey results suggest that she has high levels of disordered eating behaviours, restrained eating, binge eating, depression, anxiety, and body dissatisfaction. She also rated her overall health as very low. Her self-reported BMI puts her in the obese category. Jess has been urged to lose weight by her family and by medical professionals. She believes that she needs to lose approximately 50 pounds of weight to alleviate her chronic pain and feel overall more confident and healthier.

Heather

Heather is a 20-year-old woman of Cuban-American descent who is in a committed relationship with her boyfriend. Heather lives in New York City and works full-time in media and journalism. Heather also maintains a blog on living life with a disability. She has a university degree and is currently pursuing additional education on a part-time basis. She identified her socioeconomic status as middle. Heather was born with a left-arm congenital amputation below the elbow. She wears a prosthesis some of the time. She noted that she has become more comfortable being in public without her prosthesis only in the past couple of years because she has become more confident about her appearance as a disabled woman. Heather denied that her disability had any functional impact on her life and rated her overall disability severity as mild. She performs all transfers, activities of daily living, meal preparation, and eating independently. She reported that her disability mainly affects her appearance and, as such, can contribute to feelings of body dissatisfaction.

Heather reported that she first became concerned with her appearance and her weight at the age of 12. She recalled that she was always overweight as a child and she had lost the weight through dieting when she started high school. Heather reported that she restricted her food to the extent that she developed an eating disorder (anorexia nervosa). Heather stated that she is content with her current weight but still struggles with urges to restrict her food in order to prevent weight gain.

In terms of her Study 1 survey results, Heather has a high level of reported symptoms of disordered eating, binge eating, and restrained eating. She also appears to struggle with symptoms of anxiety and depression. Heather's self-reported BMI puts her in the normal weight category; although she believes that she needs to lose about 10 pounds. She recognizes that she may always believe that she 'needs' to lose weight due to thoughts related to body dissatisfaction. Heather has received counseling related to her eating disorder.

Emily

Emily is a 30-year-old woman of Euro-Canadian descent who is in a committed relationship with her boyfriend. Emily identifies as a Francophone Canadian and currently resides in Montreal, Quebec. Emily works part-time and also attends university. Her present socioeconomic status was reported as low-middle. Emily was diagnosed with juvenile arthritis at the age of two. At the time of the interview, Emily reported that she has been using an electric wheelchair as her primary mode of mobility. She reported that she can walk short distances. In the past few years, Emily has accepted moderate support from attendant services to transfer and to perform activities of daily living as well as to prepare and eat her meals. She reported that her disability has a severe impact on her life.

In terms of eating, Emily reported that she has struggled to maintain her weight at a healthy level since she was a teenager. She reported that she needs to be constantly monitoring her food intake because she has difficulties exercising. Her disability impacts her fine motor skills and Emily had previously avoided eating in public out of embarrassment for the appearance of her hands. Emily also noted that it took her a long time to accept attendant support services to assist her in meal preparation and activities of daily living. Since accepting this help, she has noticed a major improvement in her ability to eat healthy foods and to maintain her weight.

Emily's Study 1 survey results suggest that she has high levels of disordered eating behaviours. Her self-reported BMI indicate that she has a 'normal' weight. Emily reported that her mother has advised her to lose weight. Emily believes that she needs to lose 10 pounds to improve her appearance. She also reported that she has gained weight as the result of worsening of her disability symptoms and being unable to exercise.

Jennifer

Jennifer is a 32-year-old woman of Euro-Canadian descent who was engaged to her committed partner at the time of the interview. Jennifer is a part-time Masters-level student in Toronto. She identified her socioeconomic status as low. Jennifer moved to Canada as a young child from Eastern Europe. She grew up in Nova Scotia and moved to Toronto to pursue post-secondary education. Jennifer was diagnosed with Spinal Muscular Atrophy at the age of two. She believes that she acquired this condition as a result of receiving vaccinations. Jennifer uses an electric wheelchair as her primary mobility aid. She cannot bear weight and requires the use of a lift or help of an attendant to transfer. Jennifer uses daily attendant services for all meal preparation and activities of daily living. She requires some assistance while eating (e.g.,

cutting up food, feeding). Jennifer rated her disability impact as severe. She also mentioned that her eating is negatively impacted by the fact that her throat muscles are weak so she sometimes has difficulties chewing certain foods.

In terms of her eating history, Jennifer reported that she first became dissatisfied with her weight during high school. During that time, she recalled that she started dieting in an attempt to look more like the 'popular' girls in her high school. Jennifer reported that since that time, she has been constantly monitoring what and when she eats in order to maintain or lose weight. Jennifer noted that she has tried many different types of diets; however, she reported that she must exercise caution because of health-related problems. Jennifer discussed her frustrations at not being able to exercise, purge her food, or go on very low carbohydrate diets because of her disability.

Jennifer's responses in the Study 1 survey reveal that she has high levels of disordered eating behaviours, restrained eating, and binge eating. Her self-reported BMI suggests that she is slightly underweight. Jennifer has been advised to lose weight by her caregivers and family members. She also believes that she needs to lose about 15 pounds to improve her health and enhance her appearance (e.g., wear tighter clothing). Jennifer reported that she sought out assistance from her primary-care physician and a dietician when she wanted to lose weight in the past.

Mariam

Mariam is a 23–year-old single woman of Pakistani-Canadian descent. Mariam has a Master's degree and works full-time in Human Resources. She indicated that her socioeconomic status was low-middle. Mariam was born in Pakistan and immigrated with her family to Canada when she started primary school. Mariam reported that when she was

diagnosed with Spinal Muscular Atrophy at the age of two, her parents made the decision to immigrate because of the limited opportunities for persons with disabilities in Pakistan. Mariam explained that in her culture, persons with disabilities are feared and often not permitted to attend mainstream schools. Because of Mariam's neuromuscular disorder, she uses an electric wheelchair as her primary form of mobility. At the time of the interview, Mariam indicated that she is unable to bear weight. She uses a mechanical lift or lift from a caregiver for her transfers. Mariam also relies on personal support workers or her family to assist in meal preparation and activities of daily living. She rated her disability severity as 'severe'.

In terms of her eating history, Mariam reported that she has been vigilant about her eating since she was a teenager. Mariam believes that she probably met criteria for an eating disorder when she was 16-years-old; however, she was never clinically diagnosed. Mariam recalled at that time that she had lost a substantial amount of weight; however, her medical care team was not alerted to her potential eating disorder and, in fact, was encouraging of the weight loss. Presently, Mariam restricts her daily caloric intake. She reported that because she cannot exercise, she tends to over control her eating habits. Mariam noted that she eats a diet of 1000 calories per day; a number she selected herself after recommendations from a dietitian to eat 1200 calories per day.

Mariam's Study 1 survey results suggest that she has elevated levels of disordered eating symptoms and low self-esteem. Her self-reported BMI puts her in a normal weight category. Mariam reported that she has never been advised by a healthcare professional to lose weight, although, she was encouraged to continue losing weight when she had dieted as a teenager. She reported that her family has advised her in the past to lose weight. Mariam stated that she would like to lose up to 10 pounds for appearance reasons and also to increase

independence for transfers and other activities of daily living. She also reported that she is very conscious of her weight due to the impact her scoliosis has on her general appearance. Mariam has never received treatment for her disordered eating. She saw a dietician for a few sessions in the past; however, she did not find it helpful. Mariam also pays for private physiotherapy.

Hannah

Hannah is a 35–year-old single woman of European-Canadian descent. She works part-time as an educational assistant for students with disabilities and she is also a full-time university student. She identified that her socioeconomic status is low. Hannah struggles with chronic pain related to degenerative disks in her spine and sciatica. She reported that she has lived with her disability for 18 years. Her disability is mostly nonvisible, although she lives with chronic pain on a daily basis. She occasionally uses a cane for walking; however, most of the time, she does not use any mobility device. She also reported that at times, her pain level is so high that she requires assistance from others for transfers. She stated that her disability severity ranges from moderate to severe, depending on her level of pain. Hannah reported during the interview that she is unsure whether she identifies as a woman with a disability because she does not want to be stigmatized or viewed as 'less-than' by other people.

In terms of her eating history, Hannah reported that prior to her disability, she was a very active person. After her diagnosis, she became increasingly sedentary, resulting in weight gain. She also reported that the medications she is prescribed for her chronic pain increase her appetite. Hannah reported that weight gain has had a negative impact on her joints and results in increasing chronic pain. Hannah reported that since her disability symptoms first emerged, she has been in a cycle of restricting her food, over-exercising, and, subsequently, overeating or binge eating. She reported that when she pushes herself to increase her physical activity, she

increases her experience of pain; however, once she stops exercising, she then gains weight and suffers from more chronic pain. She was tearful throughout the interview in describing this difficult pattern of dieting, weight gain, and chronic pain that has overshadowed her life.

Hannah's Study 1 survey results revealed that she has elevated scores on scales that measure disordered eating as well as measures of depression and body dissatisfaction. Her self-reported BMI puts her in the obese category. She reported that she had been advised by numerous health care professionals/specialists that she should lose weight in order to improve her quality of life. Hannah herself would like to lose about 60 pounds of weight. However, despite recommendations to lose weight, Hannah reported that she has never received adequate support or treatment for her disordered eating symptoms or other mental health symptoms.

Kelly

Kelly is a 21–year-old woman of Euro-Australian descent who is in a committed relationship with her boyfriend. Kelly resides in Sydney, Australia. Kelly reported that since high school, her main source of income has been disability benefits. She identified her current socioeconomic status as low. She attended mainstream schooling in Australia and had an educational assistant with her throughout most of the day. Kelly was diagnosed with Spinal Muscular Atrophy at birth. She uses an electric wheelchair as her primary mobility device. Kelly cannot bear weight and requires the use of a mechanical lift or lift from a caregiver for all of her transfers. She uses attendant services and/or requires assistance from her family for all activities of daily living and meal preparation. She reported that her disability does not directly impact her ability to eat and digest food. Kelly rated her disability severity as 'mild'.

In terms of her eating history, Kelly reported that she has been actively trying to lose weight since she was a teenager. When she was in high school, Kelly recalled that she used to

purge her meals into the sink in order to avoid weight gain. She believed that she had anorexia and bulimia at that time, but she was never clinically diagnosed with an eating disorder. She recalled that her mother used to threaten hospitalization unless Kelly would eat some food. At the present time, Kelly follows a very low calorie diet (800 calories per day). She reported that when she is not very careful about what she eats, she gains weight very quickly since she is unable to exercise.

Kelly's Study 1 survey results reveal elevated scores on the disordered eating and restrained eating scales. She also reported low self-esteem and body satisfaction ratings. Kelly's self-reported BMI suggests that she is a normal weight for her height. She reported that she has not been advised to lose weight by any health care professional. She believes that she needs to lose weight to enhance her appearance and to make it easier for her partner to lift her. Kelly has never received support or treatment for her disordered eating. She was hospitalized once as a teenager following a suicide attempt but did not receive any follow-up services. Please see Table 8 for further details on each of the participants interviewed.

Data Analysis

In terms of the analyses, I began by first listening to each recording in its entirety alongside reading the transcript, and correcting any errors or missing script in the transcript, using my memos of the interview as contextual information. Next, I read through the transcript as a whole and noted any initial thoughts or ideas that emerged as a memo. I then broke down the text into meaning units. A meaning unit refers to a specific point or thought the interviewee was trying to convey, usually consisting of two or more lines of text. From each meaning unit, the meaning(s) therein were educed and represented as one or more categories. The initial categorization process was uninhibited in order to capture as many possible meanings as the

information presented. In other words, I granted myself permission to categorize meaning units to as many categories as I felt it fit so as to not limit my initial coding tree. This process was repeated across interviews.

Following the initial coding of all the interviews, an initial coding tree was developed (See Appendix E). These initial categories were then compared with each other in order to explore if higher order categories may be conceptualized subsuming the meaning of the other categories. Using the constant comparison method (Marshall & Rossman, 1995), I then continuously compared the higher-level categories with patterns in the lower-level categories as well as considered the research questions and any other assumptions or possible explanations that emerged from the data. This process was repeated across participants until the conceptualization of a single core category had been achieved. Several coding schemes evolved as the higher order categories were constantly compared to the lower categories until I reached a final coding scheme (See Appendix F). The final scheme was discussed and reviewed with my supervisory committee.

Throughout the analysis, I engaged in memoing of thoughts, assumptions, impressions, and reactions while immersed in the interpretive process in order to understand how this informed and/or shaped the research findings. Management of the data was facilitated by using N-Vivo 10 software. I consulted with my supervisory committee to facilitate validity of interpretation and categorization, as well as the effective bracketing of previous assumptions and experiences. I also contacted some of the participants if there was any confusion around the transcripts. In terms of reliability of coding, a research volunteer was trained to also code the data. Twenty-seven percent (one in four) of the interviews were double-coded by the research volunteer who had no prior knowledge of the study hypotheses. The categorizations were

compared across coders. Any discrepancy in coding was resolved through consultation with the supervisory committee. There were only a few instances of discrepancies across the four interviews coded by the volunteer; otherwise, the coding appeared to be very reliable.

Results/Findings

The core category, Surviving And Thriving In A World That Is Not Designed For Disability And Difference, captures the experience of women with physical disabilities who show disordered eating. The core category is represented by a hierarchical organization with a number of subcategories subsumed below, which will be identified through a numeric labeling system that describes first-level to fourth-level subcategories. I have provided flowcharts and labels throughout. Please see the Appendix F for a full listing of categories.

The core category signifies the ways in which disabled women understood their experiences to be separate, distinct, and different from the experiences of most other people ("everyone else"). Although women spoke generally about how their experiences with eating, weight management, and body image were different from their peers, it alone did not capture the full spectrum of the women's experiences. Women with disabilities described feeling "othered" in various domains across their lives. These feelings of being different or othered contributed to complex psychological and social responses to cope, survive, thrive, and connect with others. In fully understanding the ways women felt separate, the core category explores three ways in which women described how their experiences were different from other women: 1) Functional Differences, 2) Embodiment Differences and 3) Social Differences.

The category further captures the diverse ways in which women with disabilities respond to this feeling and experience of difference in other words, the ways they survive and thrive in the world. The challenges that encompass being different in a world not built around their needs elicits a range of responses and strategies, which could be understood as both surviving or thriving (adaptive or maladaptive), dependent on the context. Woven into each of these categories were examples of how food, eating, and body acceptance/issues were an

important aspect of responding to difference, either through an adaptive coping strategy or an immediate reaction or response. In terms of eating, weight management and body image, women with disabilities felt different in not only how they experienced eating and their body, but also how they related to other people, accessed services, and how they existed day-by-day and interacted with the world. These experiences then contributed to, and shaped, how they responded to those differences. Women also used aspects of their eating and their embodiment as methods to respond, cope, connect with, and resist their positions of difference. Therefore, it is the interaction between understanding that difference exists and responding to it that exemplifies the experience.

The full hierarchical category model is depicted in Appendix F. It includes a number of first-, second-, third-, and fourth-level categories subsumed within. Headings of each category level are formatted differently, using the APA style guidelines for fifth-level headings, with two exceptions: 1) I have capitalized each word in category title and 2) I separated each main category on separate pages for ease of reading. When appearing in the body of the text, the first letters of each category name are capitalized. In describing the categories, I used a limited number, yet representative sample, of direct quotations from different participants. The reader will notice that I have used quotations from all eleven participants.

The core category describes the experience of disordered eating for women with physical disabilities encompasses the ways in which women with physical disabilities felt different, separate and apart from the "typical" woman. It is comprised of three main domains or first-level subcategories: Functional Differences, Embodiment Differences, and Social Differences. These three domains, in turn, include a number of subcategories, themes and subthemes subsumed within.

Although the concept of difference is not always associated with some sort of issue or problem, in this context, many of the women interviewed did have negative associations in terms of the ways that they were separated out from the group or the norm. Each of the women in the study described in detail moments where they became aware of their own difference and the meaning that they ascribed to that difference.

> I think, for me, that's when you get this real awareness that you're different from other people, that you're not the same. I think that the major thing, that's when it really clicks. It's like, "Wow! I really am someone with a disability". Different isn't always looked at in a good way, that's how I see it. I just think it's just different. I don't know how best to put it, just not normal (Jess).

For most of the women, the difference that is connected with disability is not unique or something to be proud of and celebrated. Rather, difference is viewed as abnormal, separate, apart, and something to be ashamed of. The sources of the messages that disability is 'not the good kind of difference' also appeared to be widespread and varied. For some women, they understood this difference in the context of how their body used to work. For example, one interviewee, Jess, had chronic pain and arthritis stemming from a motor vehicle accident. How she understands her disability was grounded in her comparisons to her life without chronic pain and limited mobility. For others in the study, they recalled noticing that they were different from their peers because they were excluded or rejected. Below is an example of how one participant experienced feeling ashamed of her disability by messages that she received from her family.

> I was nine-years-old. We [my family] were parked in a Wendy's and I was getting out of the car. They noticed that one of their [clients] had stopped at the same Wendy's. They told me to get back in the car. It was this very awkward situation. They explained that they didn't want them to see me. It's the first time I ever felt like shame for who I was and what I looked like (Heather).

Whether participants received the message from friends or family, the media, or by simply existing within a society that is not always accessible and inclusive, all of the participants had, at some point in their lives, internalized at least some of this message. There is also an implication that the difference brought about by disability is viewed as a negative attribute or problem in society.

> I don't think anyone chooses to be different. I mean, there are certain celebrities like Lady GaGa who chooses to be different and that's totally her prerogative. Disability isn't something that you choose. It's not something that necessarily has a positive reputation in society (Heather).

In the elaborations of the other categories subsumed under The Experience of Difference, I will explore the meaning, consequences, and implications that are associated with feelings, perceptions, and the realities of being different or an 'other'. At its core, being different is not necessarily a problem. Rather, there is a significant threat to a person's relationships, likelihood, career/education, and well-being. As one of the participants describes, "There's a fear that I'll look different and that I'll be treated different" (Heather). In the next section, I will break down three ways in which participants described that they felt different from other people because of their disability status.

Functional Differences

The first of the domains or first-level subcategories describes the physical differences and medical realities of living with a body with physical limitations and impairments. Functional Differences captures the difference between women with disabilities and those without in terms of mobility, activities of daily living, and presumptions of health. Women with physical disabilities discussed how they experienced many functional differences in not only activities related to eating and weight management, but in all aspects of their lives. Here, the term functional refers to differences in medical, physical, bodily, activities of daily living, and dependency needs. For example, women with a physical disability may require assistance of a PCA or mechanical hoist using the bathroom due to physical difference needs in transferring their bodies from their wheelchair to the toilet. Further, besides these functional differences in mobility or caregiving, there were also implicit messages that their bodies were not ideal, healthy, fit, or functional.

Women with disabilities discussed their acute awareness and constant reminders that because they had a physical disability, they could never be considered 'healthy' or a fully functional human. There was also an awareness of the implicit and many times overt societal preference for fit and healthy bodies. Disability is viewed as the antithesis of health. There was a message, either generally from society, health care professionals, family, and/or caregivers, that they could never be considered active, fit, healthy, and, as a result, "normal". In addition to these disempowering messages, women with disabilities themselves described the struggle of trying to maintain their weight, be physically active, or healthy when they cannot move their bodies or engage in typical physical activity. Below are different ways, here outlined and described as second-level subcategories, in which disabled bodies are deemed separate and

excluded from the checklist of being healthy and fit. There are four subcategories (second-level) that encapsulated the experiences of women with disabilities describing how they were functionally different, including: a) Disabled Bodies Cannot Be Healthy, b) Doubly Disabling, c) Constant Uphill Battle, and d) The Cost Of Support.

Disabled Bodies Cannot Be Healthy

The first subcategory (second-level), Disabled Bodies Cannot Be Healthy, captures the experience of women with physical disabilities who felt that their disabled bodies could never be considered healthy. No matter how many preventative actions they take, there was an understanding that their physical disability would override any and all attempts and keep them classified as unhealthy, disabled, and broken in some way. All participants discussed how their physical limitations and assumptions regarding their ability and interest in maintaining their health impacted their eating and physical activity level. The participants described three subcategories (third-level categories) that captured their experiences of being constantly reminded of their absence of health and presence of disability. These subcategories included: 1) Sedentary Lifestyle, 2) Fit Is The Ideal, 3) Disability Trump Card, and 4) The "Lemon" Body.

Sedentary Lifestyle

Women discussed how challenging it was for them to be considered traditionally healthy when they were not able to move their bodies in the same way as persons without a disability. Participants described how being inactive takes a significant toll on their ability to manage their weight. They described how weight gain was almost inevitable and difficult, if not impossible, to prevent.

> It's realizing that I don't have the same activity levels and I almost feel like I have to be even more careful because I'm not using the same calories the same sort of energy that

> I'm consuming. I think that's the main reason I would say it [my physical disability] affects my eating habits (Mariam).

> Since I can't do a lot of physical activity, I do have to control how much I eat, because I do gain weight very easily (Emily).

A sedentary or mostly-seated, inactive lifestyle for the majority of the women in the study was their "normal". Most of the participants described spending all of their days sitting in a wheelchair. This was especially true for women with congenital disabilities.

> You've had many, many, many years, from the time that you were small, to put on weight, more so than somebody with an acquired disability. Because you've never had the possibility to move around in the same way, it may also be that people with congenital disabilities are on average larger in their adult life because they have had to struggle more with it [weight gain] (Jennifer).

For other women with congenital disabilities, they discussed how they gained weight after they progressed from walking to a more sedentary lifestyle. As can be inferred in the quote below, there is a feeling of powerlessness, as Emily describes how even if she eats well and exercises regularly, she still cannot override the effects of having a sedentary lifestyle.

> I've been to a bunch of nutritionists. I learned the [Canadian] food guide. I had tried to follow this but I feel that if I don't do my weekly exercise, I'll still gain weight. Maybe it wasn't tailored as much to how much activity I do. I have been using an electric wheelchair for a year and a half now so I don't burn as much calories as I used to (Emily).

Further, the experience of struggling to maintain a constant, healthy weight also generalized to women with acquired disabilities. Women who had developed disabilities later in life attributed their problems in health and weight gain to the fact that they could not physically move around as much as they did prior to the development of the disability, injury, or chronic illness that impacted their mobility.

> The weight gain has a huge impact. It sometimes leads me to eating more rather than dealing with the weight. It's hard because of my back to do the physical activity that I used to (Hannah).

Participants discussed their fears regarding how much worse their functional abilities could become if they continued to gain weight. Fears of becoming so disabled that their quality of life would be completely abolished can be read in the participants' quotes. For example, Jess, below, talks about how she fears not being able to walk at all and how that would severely impact her quality of life. Based on her past experiences of weight gain, she fears that:

> I wouldn't be able to walk at all, and not being able to just live in general. Because if it was just that I was in pain once in a while or in pain when I walk long distance then I would say okay, just stop going long distance or avoid like running. But even sitting down for too long, my leg just stays in that position and is in pain (Jess).

Further, women described a feeling of constantly being stuck in an endless cycle of weight gain and inactivity. However, not all participants found the experience completely demoralizing. Some participants had found ways to respond and maintain their weight even in their current circumstances by comparing their lifestyle to persons without disabilities with sedentary lifestyles or those with poor metabolism.

> I bought a personal training contract at my gym and the personal trainer that I was working with is also certified in health and fitness wellness coaching. I think it's this certificate from the Internet. He was into "paleo eating" and he had recommended it for me because it's prescribed for people who lead a sedentary lifestyle. He thought that many of his clients are sitting for like eight hours a day because they work at a desk and I'm sitting all the time, mostly. He thought it would be good and it's been fairly useful (Kendra).

Participants described generally combatted the sedentary lifestyle through calorie restriction. As with Kendra, almost all of the women expressed a belief that they needed to compensate for the lack of physical activity. Michelle, for example, remarked "just basically restricting is my secret weapon," whereas Carrie indicated "The only thing I've ever done is count calories. That's it." Jennifer expressed a similar sentiment by stating "The only option for me is to restrict because the other options [exercise, compensatory behaviours] are not available to me to maintain my weight or lose weight." Women further spoke about how calorie restriction was not something

that was difficult for them to learn. Rather, it was almost second nature to them. It was clear that many of the women had been dieting or restricting their food intake for most of their lives. For instance, Kelly remarked "I don't really find that it takes up a lot of time. I find that it comes pretty naturally. I think part of that is because I eat like a lot of safe foods." Similarly for Hannah, she commented: "I feel like I eat enough. I can't- I don't feel that I could fit more food into my diet on a regular basis." However, for some women, calorie restriction, although effective as a means to lose weight, had become unhealthy and dangerous. Mariam, for example, discussed how she became almost obsessive in her pursuit for thinness where she did not notice how unhealthy or malnourished she had become. She also highlighted the common experience of individuals who need to increasingly reduce their food intake in order to continue to notice any weight loss gains. Similarly to the other interviewees, Mariam discussed how caloric restriction presented itself as a readily available and easy option to control weight.

> It [restrictive eating] used to be the exclusive way that I controlled my weight. But, recently I had a little bit of a wake up call. At one point, I was going a little too far with my dieting. I was down to less than 500 calories a day…I moved down to 97 pounds, which was severely underweight…I don't know why, but for some reason, physical activity never crossed my mind. It was just, "oh this [calorie restriction] is an easy way that I can do this" (Mariam).

For other women, the challenges in long-term caloric restriction stemmed from losing control of their eating. Over-time, they noticed greater episodes of binge eating or overeating. Further, their eating became increasingly erratic, meaning it was less related to natural feelings of hunger and satiety and more related to their emotional urges.

> One thing I do struggle with now is binging a lot and emotional eating, which is weird because this was never a problem for me before. I could restrict and I was so good about it. Now, it's the opposite. I'll just eat and eat and not be hungry but then I'll restrict for two days (Heather).

Calorie restriction as well as compensatory behaviours were understood as necessary to control weight in women with physical disabilities. A sedentary lifestyle was just one of a few different categorizations that contributes to the portrayal of disabled bodies as not fit and healthy. In the next section, I describe how a narrow understanding of what is fit, healthy, and attractive impacted how women with physical disabilities experiences their bodies as both different and inferior.

Fit Is The Ideal

Besides experiencing the negative impact of gaining weight due to being inactive and sedentary, women with disabilities also discussed how their physical impairments contributed to feelings of being different within their families or their social group. The subcategory (third-level), Fit Is The Ideal, encapsulates the experience of being considered unfit in a society that promotes fitness, physical activity, and generally healthy lifestyles. In these scenarios, a healthy body does not just represent a body that is absent of fat and that is not sedentary, but there is a felt idealization of 'fit' bodies. These as bodies that can move, be active, participate in sports, and travel. In other words, bodies that are not limited by stereotypes of a physical disability.

> Seven was the first time that I realized that I was probably not thin. That was also the first time that my parents had intervened and attempted to do something about it. Some of this was positive. One of the things my mom really wanted us [participant and her twin sister] to do was to be active. She was always very concerned because I can't walk and it was harder for me to participate in sports so she was always really concerned that I wasn't getting enough activity (Kendra).

For Kendra, there was an implicit message that she needed to at least try to be fit and active, particularly given her physical disability. This encouragement was related to and intertwined within the messages to be thin. Most of the women described how being fat or overweight was not the main source of discontent with their bodies. Rather, being judged as unfit or unhealthy

was just as damaging. Jennifer, as written below, compares her lifestyle with that of her nondisabled attendants, who are the people assisting her for activities of daily living.

> I have an attendant who is super into fitness. She's got a lot of muscle tone. And she works out and she eats the way that I would like to eat, which is carb-free and lots of protein and vegetables and things like that. It's extremely frustrating because I do find myself comparing [my body] to my attendants' since they are around me all the time. I get frustrated that I can't look like them or that I can't eat like them or that I can't workout like them (Jennifer).

Although participants in the study, like Jennifer, knew that they could perhaps never have that ideal body that would be understood to be fit, healthy and attractive, it still contributed to feelings of envy as well as frustration with themselves and their disability.

On the other hand, some of the participants found a sense of empowerment in striving to be 'fit'. However, the women described how they had to revise the traditional notions of fitness to accommodate their disabled bodies. To accomplish this, women had to begin challenging traditional methods to achieve health (e.g., exercising five times per week, eat according to Canada's Food Guide, etc.). Women had to discover their own healthy lifestyle balance, even if the end goals were completely different or inconsistent with traditional recommendations for people without disabilities. In the quote below, Hannah describes her struggle with tailoring her exercise program in a way that promotes healthy living and does not exacerbate her chronic pain issues.

> It's really easy to fall into a rut. I do, often. But, I think by maintaining physiotherapy and a good daily eating habit, it is about trying to get back a bit of control or some sort of a normal in a world where you don't really have a lot of control. You can't go in and fix your spinal disc problem (Hannah).

For many women with physical disabilities, finding a healthy living balance meant letting go of the idea that weight loss was the ultimate measure of health and fitness. Women further explained that there was often a lot of confusion surrounding the amount and intensity to which

they should exercise. For some, it was even unclear whether physical activity would help or harm their bodies, strength, and/or mobility. Each woman had to determine her own guidelines and recommendations for physical activity. Interestingly, most women in the study had agreed that they needed to integrate physical activity into their lives; however, they also had to let go of the idea that physical activity involved regularly scheduled cardiovascular or strength training at a local gym. For many, engaging in range of motion or stretching was their physical activity.

> [Caloric restriction] used to be the exclusive way that I controlled my weight. But, recently I had a little bit of a wake up call. I have been doing a lot more physiotherapy, going to the gym, swimming, and just staying active. I think that the staying active component didn't really stem from the watching my weight. It came from just being healthier, overall (Mariam).

For Mariam, she had to experience a health scare of over-restricting her food to realize that she could and should engage in regular activity. Others shared similar experiences of finding their healthy activity routine. For instance, Heather describes how "I work out not just to be thin, but to feel better. I think it's really important that instead of seeing how the way your body looks, to celebrate what your body can do."

Although the traditional notion of fitness can be damaging and unhelpful for the health and well-being of women with disabilities, finding their own adapted form of physical activity could be very empowering and act as a protective factor against body dissatisfaction and disordered eating.

Disability Trump Card

Some participants discussed the feelings of powerlessness in realizing that no matter how much they engage in healthy activity or eating, it would not matter: they would always be considered disabled and, as a result, not healthy. The Disability Trump Card refers to the way in

which having a physical disability overshadows and discounts any other attempts to improve health. Because disability is the antithesis of health, one cannot be healthy and disabled. Participants described their hopeless feelings with regards to the constant cycle of monitoring their food and attempting to get some form of exercise. As one participant described: "It doesn't matter how many kale smoothies I drink, I will always be understood as disabled and not healthy" (Carrie). Below, a participant describes what she refers to as an "endless" cycle. A metaphor that could be used to describe this would be a hamster running on a wheel. Trying to maintain fitness, health, including a healthy weight, with a physical disability takes a consistently immense amount of time and energy; however, the payback, or the distance run by the hamster, is not always apparent. Yet, at the same time, the consequences of stopping the efforts are disastrous to a person's health and wellbeing. Below, this quote from Emily exemplifies this experience.

> Since I can't do a lot of physical activity, I do have to control how much I eat because I do gain weight very easily…It's kind of an endless cycle. I am going to have to do that [watch my eating] all my life if I don't want to gain weight (Emily).

Women also explained a feeling of injustice or unfairness at the fact that they have to put in so much effort into their health yet are never understood as healthy or fit. For them, the consequences of not attending to their health via diet or exercise and gaining weight are amplified in comparison for other women, and that becomes frustrating. For other participants, it helped them to compare themselves to the norm and respond accordingly. For example, as described below, one participant compares herself to an able-bodied person with a poor metabolism who cannot exercise. In that sense, she is able to get a handle on the situation and intervene to stop any additional weight gain.

> I don't worry much more about food than somebody else who has a poor metabolism and who has to really watch what they eat. But the difference is, that if that person

> wanted to go and work out, as many people do, that's something that I can't really use as a calorie burning mechanism. (Jennifer).

Although some participants had discovered different ways to ameliorate health consequences of inactivity and eating unhealthily, there is still a feeling of being dealt a 'bad hand of cards' and the unfairness associated with this. In this category, disability status was the main factor that contributed to the women's perceived lack of healthy and fit bodies. Here, physical disability is mostly viewed as a permanent factor without any opportunities to reduce or eliminate its negative impact on health. For some women, this knowledge that their physical disability trumped any other negative impact on their health actually granted justification and permission to not stress about eating healthy or exercising.

> Sometimes I feel like, "Really? I have arthrogryposis. I have scoliosis. I have a breathing machine, actually two breathing machines and an electric wheelchair. Really? I can't eat this donut?" Most of the time I feel like, "well I'm already in a wheelchair, I can have a burger and fries." It's definitely not healthy but it's my own rationalization (Amy).

Taken together, the perceived overshadowing negative impact of physical disability on one's health contributed to feelings of powerlessness as well as the disengagement of potentially health promoting behaviours such as healthy eating and physical activity.

The "Lemon" Body

The final third-level subcategory, The Lemon Body, captures the experiences of many of the women with disabilities of having a different standard of health than most women without disabilities. To live with a disability is to live with a body that is unpredictable and can frequently struggle with various health problems and functional changes. The title of having a Lemon Body was used to capture the idea expressed by women that on any given day, things can unexpectedly give out or stop working. This included difficulties such as chronic pain,

fatigue, muscle aches, stiffness, breathing difficulties, swelling, sleeping difficulties, and so forth and contributed to high levels of distress and frustration.

> My body has not been responding the way it should to pain medication and physical therapy. Why is it that certain people have to go through these things? Because I'm Christian, I always consider why would God decide that certain people would have to go through so much like extra struggle? Life itself is not the easiest thing to go through, so why would some people have to go through extra challenges through their days? I guess it adds to the not being able to control things. It's like we are not allowed to control our destinies (Jess).

Challenges with their health and bodies had an impact on eating, body satisfaction and weight management.

> I'm constantly in pain. Previously, I'd been walking on my own but, as time went on and because it was degenerative, I started using a cane to move around and alleviate the pain. It was either that or I continue to take pain medications and I'm really not a fan of medication because of the side effects (Jess).

The metaphor of The Lemon Body describes the experience having bought a second-hand motor vehicle, which could be dependable and functional, but perhaps on a different level in comparison to a new vehicle. This also meant that women with disabilities experienced a lot of maintenance (e.g., rehabilitation, medical treatments, etc.) to upkeep their bodies and their quality of life, which can itself begin to become a large part of their identity and their quality of life. As Mariam described: "You have a lot of medical visits. You then start seeing yourself as a series of [medical] complications." Furthermore, the unpredictability and health problems were also caused by their frequent treatments and other maintenance attempts, such as Jess's description above of medication side effects. Regardless of their origins, health problems and unpredictability was understood amongst participants as part of what it means to live with a physical disability. Some participants struggled more with health problems at any given time, particularly those with chronic illnesses, episodic, or newly acquired disabilities.

> It doesn't always affect me, but when it does, I can become like completely immobile from the waist down. On a daily basis, there's a numbing pain. It impacts me when sitting or standing for long periods of time. It affects my concentration. I get irritated because I've been sitting for a long time (Hannah).

Sometimes these medical issues and unpredictable bodies created difficulties and complications for women who struggled with both eating disorder symptoms and a physical disability. For instance, Michelle stated "I struggle with bowel issues and I have a Gastroenterologist. He knows the whole eating issues and also that I have cerebral palsy. He struggles often to find out which symptom is which disorder." Similar to their experiences of their bodies, they also experienced a specific-type of unpredictability with regards to their mobility devices, transportation and support systems. The women needed to depend on a number of situations and actions to be working in order to function in the world. Each of these in turn impacted the woman's ability to eat healthy and engage in other healthy practices.

> I have mobility problems. I don't have a lot of energy. I need attendants to cook for me and do groceries. It takes a lot of space in my life. Planning everything. It needs to kind of include arthritis. When I'm going out, when I work, how I spend my energy, and things like that. It's definitely some trial to my existence (Emily).

Oftentimes, they were stymied by a broken wheelchair, last minute attendant cancellations, and unexpected delays within specialized transportation systems. Unlike women without disabilities, one glitch in the system would result in being unable to function or perform the planned activities.

> I find that my disability affects me the most in terms of transportation and personal care. I need to book rides and make sure my routes are accessible. I need to also plan when to use the bathroom so I need to time my day around being in certain areas with staff who can help me with the washroom (Amy).

In more ways than one, women with disabilities experienced difficulties with their bodies and other dependent systems that contributed to feelings of poor health, unpredictability and unproductivity. In the next few quotes, the women describe how their disability and health

problems, specifically energy levels and chronic pain, have impacted their productivity, functionality, and work situations.

> I've had to reduce my hours. I had an incident where it inflamed my disorder and I couldn't stay in the field that I am in [Special Education]. Those things definitely had a huge impact as of recent (Hannah).

> When it becomes too much, that's when I feel like I can't function and some days I'm not able to get out of bed or stay asleep (Jess).

> I do have like days that I'm just not productive. I feel a lot of guilt at not being able to keep up because I am a translator. It requires a lot of focus and sometimes it's just not there. There are days when I just do nothing (Emily).

This also occurred for some women in social situations. Hannah recalled how emotionally frustrating it was for her to maintain her friendships with her current Lemon Body due to unpredictability around pain issues. "If friends say, 'Let's go out' or 'We just want to go to a coffee shop.' I would always say no" (Hannah). Within a society that values efficiency and reliability, women with disabilities with their Lemon Bodies frequently felt as if they were falling short and engendering harmful societal stereotypes of being burdensome or traditionally unproductive.

In response to having these unpredictable bodies, women reported using food and restriction as ways to manage both the emotional distress as well as control their bodies themselves. For many of the women who related to The Lemon Bodies category, health problems, particularly chronic pain, were highly tied with disordered eating. Women attempted to lessen their disability and pain via weight loss. As Emily put it, "because a lot of my diet is always tied to trying to alleviate pain." They also tended to cope with stress associated with health issues via eating, oftentimes binge eating. Jess, who struggles with chronic pain, described her use of food to distract herself from stress below.

> I guess that's why I eat a lot. I just sit and eat cereal because I need to feel better. So, I eat or I binge watch TV, which is not very good especially with school. But, it's not like I try to do other things. My go to stress method is eating or watching TV. Sometimes, I try to write but it's counterproductive because I start thinking about things I wouldn't be thinking about, like again the [greater] self-awareness or I overanalyze certain things. Eating makes me feel better because I can eat something sweet again, like cereal or a cookie. I'm trying to avoid [eating] that because I'm trying to diet again (Jess).

There was a strong connection between self-blame due to perceived inability to lose weight, increased health issues and subsequent disordered eating (binge eating, restricting, purging) to manage the resulting negative emotions, such as shame, guilt, grief, and anger.

Doubly Disabling

The second subcategory (second-level) under the Functional Differences category describes a meaningful difference that the majority of women with disabilities ascribed to – that of being more functionally disabled with excess weight in comparison to women without disabilities. Obesity represents greater disability in an already 'compromised' body. Subsumed under this category are the subcategories of: 1) Attempting Cure At Gunpoint, and 2) Constant Surveillance, which each explore the different ways in which women described how they themselves, as well as others in their lives, have been highly motivated to avoid become increasingly dependent and immobile by being overweight or obese.

In this category, women discussed how much higher the stakes were for them in gaining any extra weight. For these women, having excess weight makes them increasingly more disabled, which in this context, means that they are much more dependent on other people for activities of daily living, they have increasing chronic pain and health problems, they cannot move as easily in a body that already has difficulties moving and they are withheld necessary health and quality of life improving attributes, services, and activities. In these descriptions, there was an underlying assumption that mobility and independence are necessary elements for

a decent quality of life. Below, Mariam describes the consequences for her of not losing excess weight or gaining more weight.

> The more weight I have, the less independence I will have because I will not be strong enough to be able to move around as much. The other part is that you will be completely dependent, or won't be able to help yourself out, which would be worse than what's already there (Mariam).

Below, Jennifer further comments on this threat to quality of life and well-being.

> There are a number of fears. I do think about how it can impact my health and my disability. I feel that being heavy actually makes me more disabled. Because I do sit all day, that's a lot of compression that's going straight to my ass. When I lie down, I have rods in my back. And I already have quite a bit of pressure that falls on my tailbone when I am lying flat on my back. No amount of cushioning in the world is going to protect you forever from bedsores and from skin breakage. I worry about how it impacts me as a person with a disability, it makes me more disabled (Jennifer).

In this quote, Jennifer discusses some significant health issues that would seriously compromise her life and even possibly kill her. There was also a sentiment in the interviews with the women that it would be almost preposterous to make your situation as a disabled woman any more difficult than it has to. In addition, there is an assumption that a person's weight is primarily within their control, meaning that a person makes a decision to lose or gain weight, unlike their physical disability. Furthermore, these pressures that women in my study experience to 'decide' to lose or put on weight are not simply messages that they receive from other people (although this occurs as well), but rather they are mostly based on their own past eating and weight management history. Women would describe how they lost weight and/or gained weight in the past and, therefore, can do it again if they were sufficiently motivated to do so. Below, Emily describes this process in her own life.

> I do feel it. I didn't make it to obesity [BMI] but I was overweight for maybe six months, a year ago. I felt it on my joints. It was difficult to move. Then I was able to manage and go back to normal weight. And it definitely was easier to walk and to move. And [there was] less pain on my joints (Emily).

The Doubly Disabling category also captures the guilt and shame that are inevitably associated with weight gain. Some participants likened this with: “choosing to smoke cigarettes when a person has lung cancer”. It would be unimaginable for a person to decide to smoke in spite of the knowledge that it will cause them further harm and suffering, similar to a disabled woman choosing to put on weight knowing that it will make her more dependent and immobile. This category further touches on the constant comparison to others that the women in my study engaged in. There is always more to lose in terms of independence and mobility, even among persons with disabilities. In the text following, I will elaborate on the subcategories that comprise the Doubly Disabling category.

Constant Surveillance

This subcategory (third-level) describes how the women felt as if they were always under surveillance from of the people in their life. Related to how obesity is experienced as disabling, this constant surveillance was believed to be motivated by efforts to ensure the woman with a disability does not gain weight. The surveillance included activities, such as eating, drinking fluids, toileting, showering, dressing and other body-related activities. Due to the increased dependency on other people, such as parents, partners and paid attendants, there was the constant experience of lack of privacy, autonomy, and scrutiny by others. As Michelle described about her attendants: “They knew what I ate and what I didn't eat. More than probably anyone”. This both contributed to increasing disordered eating behaviours as well as a protective factor that made it difficult for them to engage in any unhealthy dieting or other disordered eating behaviours. For some participants, the constant surveillance and control of meals was more of a practical necessity, seen in the quote below by Amy that describes how her mother provided her meals.

> I think she [Mother] was more concerned at how the doctor was concerned. She wouldn't deprive me. She would make [me] the same thing that everyone else was eating, just in a healthier version. There was a lot of portion control, for sure, but at that time she was also lifting me so maybe she was concerned for herself (Amy).

For others in the study, the feeling of being constantly supervised was less of a practical necessity, but emerged from beliefs other people attributed to the disabled woman's ability to be autonomous and independent. Women described feeling patronized and underestimated in their ability to manage their own food, bodies, and health. Below, the participants describe their personal feelings in response to being under constant surveillance.

> Socially, family parties were the worst because they would sit me down and watch me [my aunt and my cousins] and I just felt like they were treating me like an infant and I couldn't hide. I couldn't do what I normally did so that was very tough (Heather).

> They [the attendants] were bringing their concerns to the management and the management would come back to me. They would write me emails like, "you're only eating vegetables. I'm hearing this from all the staff and their concerned" (Michelle).

Even in the absence of overt comments or opportunities to control food, eating, and body practices, women still experienced other people in their life as constantly monitoring them. This included feelings of being constantly judged by others based on their food choices, body size, physical activity level, and so forth.

> They [the attendants] don't comment on what I eat, but I think that sometimes they are judging me anyway. Maybe they are thinking about what I am eating and thinking that it's not great. Or that I am either eating too much or not enough. (Jennifer).

The women in the study also expressed how this constant surveillance also had a protective quality in that it can encourage health and prevent disordered behaviours. Jennifer described how her life and the dependency that her disability meant that she could not develop an eating disorder because people would begin to notice these behaviours and then they would act on them more so than those without disabilities.

> Well, in my case, because I do have my mom preparing a lot of my meals and giving me food, the truth of the matter is, if I start really starving myself, it's way harder to conceal. I will say that's probably a huge protective factor, although it's also very annoying. The fact that I have to be accountable to somebody for what I am eating. It goes back to the lack of privacy that people with disabilities often experience (Jennifer).

> Even your washroom would be a bit less private than someone else who doesn't need an attendant. It's not like I can get on my knees in front of my toilet bowl and just puke (Jennifer).

Taken together, constant surveillance was described as both helpful and harmful for women with disabilities attempting to develop healthy eating habits.

Attempting Cure At Gunpoint

This subcategory (third-level) captures the idea expressed by the women in the study that being heavy or unable to lose weight has tremendous consequences for a person's health, independent living, and quality of life. The expression "Attempting Cure At Gunpoint" emerged as a metaphor for what the participants were describing in their interviews; that if they did not "choose" to improve their life by losing weight, they would be ultimately pulling the trigger on their life, well-being, and happiness. I used the word "Cured" as an extension of the Doubly Disabling category to signify that becoming less heavy or less fat was seen as a way of achieving less functional disability or a form of "Cure". The terrifying threat of weight gain appears to be both based in reality and also somewhat exaggerated to frighten the individual, similar to the metaphor of being threatened at gunpoint. Not losing weight and becoming more disabled in a world that does not accommodate disability would be hugely damaging for the person's independence and mobility. In the quote below, Kelly describes how losing or maintaining her weight would help her to feel like less of a burden to her boyfriend and her caregivers.

> I feel like I should be a more reasonable weight. Maybe a little bit skinnier than reasonable but not overly. I have a boyfriend who picks me up so I don't want to get too heavy. It's just easier on my carers who roll and dress me (Kelly).

Of note, she refers to her ideal weight as "reasonable" or "a little bit skinnier than reasonable," which implies that maintaining or losing weight to make oneself easily transferred and assisted by others is obvious, common sense, and factual. For women with physical disabilities, excess weight is not just damaging for their health, but it can also be damaging for their care and their relationships with others. In almost all interviews, there was an assumed deleterious impact of excess weight on health. Some participants, as described below, appeared confused about the question by the interviewer regarding why gaining weight was damaging for their health and well-being, again, as if the answer is so imbedded and obvious that it needs no explanation.

> …because there would just be more fat. It's hard enough for me to move the parts of the body that I have now in terms of muscle and shifting. I can't imagine doing it with an extra twenty pounds. Your [wheel]chair's also built customized for you. If you gain twenty pounds, it'll change your posture and your clothes (Amy).

In addition to the negative impact of excess weight and fat on health and mobility, the women interviewed also discussed how an increasing body size could have a significant impact on their mobility devices. Women discussed how needing a bigger wheelchair or cushion was practically complicated (e.g., fitting through doorways) and represented some sort of personal failure, similar to how going up in a clothing size or weight classification would impact a woman without a disability.

> In the last couple of years, I think they did change the size of my seat cushion, from a fifteen inch to a seventeen inch, so that was already like "Oh my god. My ass is too big. If I get any bigger, I am going to have to go into a bigger chair" (Jennifer).

Further, on top of feeling personally disappointed in oneself for gaining weight and having to get a bigger wheelchair cushion, participants discussed implicit messages they were given from family members and caregivers signalling that if they gained any more weight, they would be

disabling or limiting themselves more than they already were. Below, Kendra discussed the praise and warnings that she received with regards to the size of her wheelchair.

> When I was six, I got my first wheelchair and I was something like 12 to 14 inches wide. They make the chair taller and wider [16 inches] than you because you have to keep it for at least four years. Then, I remembered the next time I had to get a wheelchair, it was a huge compliment from my mom. She was really happy that we [twin sister in wheelchair] were still only 14 inches wide. From then on in, it became you can't get any bigger than this 16 inch wheelchair because if it's 18 inches we're going to have to renovate the doors (Kendra).

The consequences for gaining weight/increasing in size were problematic and threatening to persons with physical disabilities. Further, they weren't necessarily all health related, but rather the benefits of being small, easy to lift, and able to fit easily into spaces was also to the benefit of others in their life (e.g., caregivers, family, partners, etc.). Mariam describes some of the comments she has received from her attendants with regards to her weight gain that exemplify how women with physical disabilities are encouraged to remain small, light, and not burdensome. She recalled statements such as, "Things like: "oh you're going to get so big and that you'll need three people to help you or whatever." Mariam elaborated how these comments impacted her, stating "Well, I mean, I don't think that's an appropriate comment to be making but I think that it almost instilled fear, right. I think it sort of hits on a fear." Mariam further describes the impact that these comments have on her life. Weight gain becomes threatening and scary. Women with physical disabilities are accustomed to feeling like they are using a lot of resources (e.g., care, wheelchair cost and repair, etc.) to live independently. Therefore, there is a societal expectation to be grateful and minimize the burden as much as possible. Emily further elaborates on this fear of needing more help and assistance from others.

> I fear needing more attendant care. To accept that [needing help] was difficult. I'm overall scared of losing my independence. If gaining weight leads me towards that path then it's definitely scary for me (Emily).

Constant Uphill Battle

Constant Uphill Battle is the third subcategory (second-level) subsumed under the category Functional Differences for persons with disabilities. It refers to the experience women with disabilities discussed in which achieving a healthy lifestyle and a thin, healthy body consists of a never-ending battle between the women and the multitude of barriers that they are up against. In this category, women described this battle as draining, difficult and disempowering. Within this category, there were two subcategories: Prone To Weight Gain and Nutritional Purgatory, described below.

Prone To Weight Gain

The subcategory (third-level), Prone To Weight Gain, describes the physical challenges that women with disabilities encounter that make them more likely to put on weight. Part of the issue that contributes to weight gain is the inactive/sedentary lifestyle. However, there is also a psychological component that dictates women with disabilities feel they need to be constantly on guard and alert to potential avenues for weight gain, particularly given the compounded consequences of weight gain and excess fat described in a previous category. The way in which women spoke about being constantly self-vigilant resonated with a metaphor of a battleground where removing their guard has or could have disastrous effects.

> Well, unfortunately because I haven't been paying as much attention to my eating lately because of all these other things that are happening in my life, I have put on a few pounds. It's because I've started reintegrating more carbs into my diet and I'm basically eating like a normal person. When I eat like a normal person, I just gain weight. For me, if I say "I want to lose five pounds", that's a frickin' month of, not starvation, but really, really, really paying attention to what I am eating and not eating things that I might be craving, such as, chips and chocolate. It's very difficult (Jennifer).

In response to an interviewers questioning regarding the potential consequences of 'taking a break' from the constant self-vigilance, the participant further alluded to how something that is not a big deal for women without disabilities can be a significant issue for women with disabilities, causing them to gain weight that cannot be lost with exercise.

> One episode [cheating on her restrictive diet] will actually make me put on a pound. I actually know of other people where physiologically, the same thing happens to them. They will have a piece of cake and, the next morning, they weigh themselves and they've put on a pound. But the difference is that they can take it off really quickly and I can't. (Jennifer).

In the next example, the participant explains the impact of this 'constant battle'. Specifically, she discussed how psychologically taxing it is for her to constantly be devoting her time and energy to physical activity and monitoring her eating.

> It takes a lot of dedication on my part, [including] physio[therapy] and trying to remain calm, because stress also doesn't help this situation. It's being dedicated with stretches, exercises and trying to stay as physical as I can, because that could help things get back into place (Hannah).

Women in the study elaborated that after many years of fighting this battle and being under constant 'guard', eventually, it contributes to feelings of powerlessness and hopelessness. Whether it was through exercise and/or diet, women with physical disabilities felt that they were never going to be able to succeed or achieve this balanced lifestyle.

> When it's [weight loss] taking so long, I feel like my motivation is so down. I have a lot of days where I think: "Why bother?" It feels sort of hopeless. Because it's going to happen again. Even food-wise, I eat so well but I'll still gain the weight. So why not just eat whatever I want? (Hannah).

After putting so much effort into trying to be healthy and lose weight, some of the women further discussed urges to simply give up altogether. Many spoke about accepting their fate and "enjoying the ride," so to speak, and eating whatever they want. Another frequently cited reason why disabled women felt that they were Prone To Weight Gain was that almost all of

them endorsed using food to manage their emotions. As Amy explains "I don't feel like I have a big appetite but I do love food. I feel like a comfort with some foods. When you swallow it, it does calm you down." Many other participants spoke of using food and eating as an escape from multiple burdens and pressures that they experienced on a day-to-day basis. These stressors included many of the themes described earlier in the first model including, but not limited to, difficulties navigating complex medical support systems, facing environmental barriers, isolation and rejection of peers and potential romantic interests, struggles with attendant care and other caregivers, and impairment-related difficulties (e.g., chronic pain, weight gain, mobility challenges). Women spoke about how immediately pleasurable and calming it was for them to eat their comfort foods. Further, they also noted how both addicting and reinforcing it was for them to eat. As such, they were prone to overeating and feeling out-of-control while eating (i.e., binge eating).

> I'll be really stressed. Then, I'll make a whole bowl of pasta that I know should be three servings, but I'll eat it all at once. In the moment, it goes so quickly. That's why sometimes I say it's like a drug that you feel in that instant. Usually, it's two bites of pasta and I'm already full but I keep eating. I don't even think I really know when I'm full, I just keep eating until I get really sick (Carrie).

Women spoke about how this method of coping was reliable and worked fast. As a result, they felt that they tended to overuse it. For instance, Kendra reported how eating certain foods helps her to receive a momentary boost in mood, like a drug, yet it can also undermine so-called healthy coping strategies.

> I think I use it [food] as a drug in the sense that it provides a really quick momentary high. If something upsets me, instead of working through all the pieces of what upsets me, for example: "what am I going to do about it? How do I feel?" You eat a cookie and your serotonin levels go up. There's that sugar rush and it momentarily solves the problem (Kendra).

Taken together, women with physical disabilities described both physical and related psychological reasons why they feel prone to weight gain and also why they feel powerless to halt it.

Nutritional Purgatory

This subcategory (third-level) refers specifically to the experience of disordered eating with physical disability. Specifically, women felt that their disabled bodies made them more likely to engage in disordered eating due to factors such as scheduling necessities, medical or functional needs, and their propensity to weight gain. “If I wasn't in a wheelchair, I’d be a really fit, healthy person with an active lifestyle” (Kelly). At the same time, their disability also prevents them from developing certain symptoms of disordered eating, such as binge eating or purging. The Purgatory refers to the ‘in-between’ state that women with disabilities feel stuck inside which bridges the worlds between having a clinical eating disorder and healthy eating. As Jennifer explains below, there is a feeling of being ‘trapped’, as if they can never truly achieve balance in their healthy eating like they imagine a nondisabled woman could.

> Well, sometimes you feel like that’s what you want to do [purge by vomiting] and, in my case, I can’t, because of my disability. So you’re sort of stuck in this nutritional purgatory. You can’t really do all the bad stuff that you really might do but you also can’t eat the stuff that you want to eat (Jennifer).

This subcategory further reinforces the feelings disabled women experience of being separate or apart from others. When describing how their disability both prevents and makes it more likely that participants have an eating disorder, Nutritional Purgatory is explained as a punishing place that drains energy and it further highlights another contributing factor to the challenges associated with healthy eating with a disability.

> It’s a double-edged [sword]. It’s like, because I have a disability, I’m actually more prone to eating disorder, but I can’t have an eating disorder because I have a disability. It’s sort of this vicious cycle. (Jennifer).

Extending the Nutritional Purgatory category of existing between the boundaries of having an eating disorder and normalized eating, a few of the participants described symptoms of disordered eating that only disabled women would experience. For instance, Amy explains how she uses her breathing machine as almost a compensatory behaviour so that she can eat more food.

> Sometimes, I binge eat. There are times when I'm really hungry. If I know on an evening, a Friday or Saturday night, that I'm at home and I have my breathing machine, I'll eat because I know that I have my resources here. But, it's getting more and more difficult to do that, particularly going to a restaurant where I'm not sure what time I'll be home (Amy).

Although not understood as a traditional compensatory behaviour as understood in eating disorder literature, Amy uses her breathing machine as an instant 'fix' to manage her breathing issues following an episode of overeating. Apparently, the breathing machine helps expand lung capacity that becomes limited from an expanding stomach. Like other compensatory behaviours, Amy's act assuages her level of guilt and shame that resulted from knowingly eating more food than she 'should'. It also grants her permission to overeat.

> *Interviewer*: It's interesting when you were talking about that, it sounds a lot like a person without a disability who eats a cupcake and then they have to go to the gym for an extra hour. It sounds like sort of what you're saying: "Oh great! Well, now you have to wear your breathing machine for an extra hour"
> *Amy*: Yeah, I would say so. Yeah, with no shame.

Some of the participants further expressed the belief that they would not have 'had' to engage in disordered eating behaviours if they didn't have a physical disability. For other participants, they discussed how their need for attendant services for daily functioning created an environment that promoted eating disordered behaviours, yet simultaneously, made it difficult to engage in symptoms due to the lack of privacy.

> I think that life, especially if you live with attendant care, has to be rigid anyway. Then, to struggle with an eating disorder exacerbates the fact that you're in this schedule. It makes it easier to stay so stringent about things. My therapist said that my personality fits someone with an eating disorder; the way that I come across and the way that I live my life (Michelle).

In this situation, the participant discusses how her disability status hindered her recovery as it made it difficult to be less rigid, more spontaneous and challenge her disordered thinking style that contributed to eating disorder behaviours like restricting food intake and avoiding unsafe foods. Another participant discussed how her physical disability aided in her weight loss and aided her eating disorder symptoms. For her, during the years that she had an eating disorder, not being identified by her family or doctors was important as she wanted to achieve a thin body. In this case, her disability made it possible for her to lose weight and it also hid her disorder from healthcare providers, as low weights are common in persons with cerebral palsy. As Michelle states "I think that cerebral palsy makes it easier to burn calories and to get to those crazy low weights."

On the flip side, the described state of Nutritional Purgatory for women with disabilities also prevented them from developing an eating disorder. Because of the medical realities and functional limitations associated with their physical disability, they experienced frustration at the fact that they could not engage in disordered eating behaviours (e.g., binge eating, purging, over-exercise, etc.) that they presume other women without disabilities can choose to engage in. In this case, it was explained as a mixed blessing. On one hand, their disability is protective but, on the other, there is a feeling of loss or envy in the fact that they cannot engage in these behaviours, even if they know that they are unhealthy and damaging. There is an alluring quality that is connected with eating disorder behaviours. The Nutritional Purgatory category captures the feeling that women in the study described of wanting to, but not being able to, have

an eating disorder. On one level, she knows these behaviours to be unhealthy or "bad", but she still expresses a feeling of missing out on some experience which she believes she has lost, particularly given the fact that she feels the reason that she would need to engage in these behaviours in the first place is her disability.

> It's very similar to not wanting to put on excessive weight. If I were suddenly to decide to become bulimic or anorexic, because of my disability, I'd probably die a heck of a lot sooner than my neighbour who was anorexic or bulimic. I am putting it very crassly but if I suddenly decide to throw up all my food - and yes, of course, it has crossed my mind as it does any woman, I think. Or, any person who is trying to lose weight and just binged on lots and lots of unhealthy, crappy junk food - if I were to do that, and start doing it on a regular basis, it would throw my electrolytes through the window. I would end up in the hospital, not after several years, but after probably two or three times of doing this. It's not so much that we're at less of a risk for disordered eating. It's just that we realize it will kill us faster (Jennifer).

In the above quote, the participant explains that women with physical disabilities are not immune to thoughts and attitudes that accompany disordered eating, rather, physically, some people cannot engage in these dangerous behaviours. Interestingly, she emphasizes the commonality that she believes she shares with most women: that of wanting to purge after binge eating on unhealthy 'junk' food. Therefore, it is not her disordered eating that sets her apart from other women, rather it is her disability that does not allow her to act on these 'common' female thoughts or attitudes.

> It's definitely the thing [medical risk] that has kept that at bay, which is also frustrating. I don't like the fact that I can't binge on a large amount of food. Not on a regular basis, but sometimes you go somewhere, you eat way too much and you just want it out of your system. It's not that you're bulimic. I've known other people to have this very heavy feeling after a meal and they feel like they are nauseous already so they just throw-up. I can't do that. I'll end up in the hospital faster than I can say "binge and purge" (Jennifer).

For other women in the study, they discussed a similar situation where the limitations or medical realities of their disability prevented them from engaging in eating disorder behaviours,

despite their initial need to lose weight being tied to disability. Amy, for example, discussed how she is careful not to binge eat because it would negatively impact her breathing.

> I think that I just eat smaller portions because of my breathing. It's the same idea but for a different reason. It's been a journey but it's always a love and hate relationship with food. I feel like it's better than it was before because I have more control over it now (Amy).

The category of Nutritional Purgatory was the last category under how managing a healthy weight with a physical disability is a Constant Uphill Struggle. Next, I will outline how participants felt different in the area of seeking support or treatment for healthy living and eating.

The Cost Of Support

The Cost Of Support is the third subcategory (second-level) under the Functional Differences subcategory. It refers to the complicated system that women with disabilities described when seeking support from healthcare providers and/or caregivers/family members. Due to the women's functional differences and medical needs, they described various experiences in which their health, wellbeing, and daily routine were compromised, disrupted, or completely abolished. Although I have categorized this under the subcategory, Functional Differences, it is important to note that women's physical impairments were not the cause of these differences in receiving adequate support and/or treatment. Rather, I have outlined a complex interaction between the participant's disabled body and a society that does not often anticipate or accommodate differences in embodiment and the needs as users of support services and treatment/prevention practices.

The Compromise

In this third-level category, The Compromise refers to the experience that participants described when they had to depend on other people to access services and fulfill their day-to-

day activities and routine. For the majority of participants, having to depend so heavily on other people to perform basic functions such as using the washroom, showering, eating and drinking had a substantial impact on their lives. Although most of the participants were accustomed to having other people assist them daily, they did express that there was typically some amount of compromise that they made on a moment-to-moment basis in their routine. In these situations, the women's health and functional needs were compromised to accommodate the caregiver.

In terms of eating and health, it was found that women with disabilities have a lot of factors to consider when deciding what/when/how to eat, exercise, seek out treatment or support and use the washroom/shower. Below, I explore different ways in which the women discussed how they compromised their routine and health.

Strict Routine

The first subcategory (fourth-level) under The Compromise refers to how women with disabilities manage their day-to-day needs while requiring support of an attendant. Naturally, this strict routine had a large impact on their eating and any attempts to eat health and/or restrict their food intake. All of the women who required attendant services (seven in total) discussed the stress and precision with which they managed their routine. Women discussed how vital it was for them to schedule their eating and drinking in a way that they could predict when they needed to use the washroom given that they had scheduled attendants who would assist them at very specific times throughout the day. In this Strict Routine, there is no room for approximation or error. If their schedule is off, even for a small amount of time, the results can be disastrous.

> I think it's like a triangle. I balance my eating with my attendants with my breathing. Especially at work, if I know I'm going to have a busy afternoon or I'm doing something strenuous after work, then I'll make sure not to eat something that I know isn't going to make me feel heavy. I know that will affect my breathing and make me

> feel lethargic. My body is spending time digesting the food and that will make me tired. It's like a constant battle. It's frantic but also very timed. For me, a fifteen-minute difference between when I should be eating versus when I eat is a big deal. I don't really see that among other people. It's like a scheduled frantic (Amy).

Here, Amy discusses how stressful it can be to adhere to this Strict Routine. Further, she identifies this as a meaningful difference between herself and person's without disabilities. Similarly, Jennifer discusses how her "scheduled frantic" life impacts her eating.

> Sometimes because of my schedule and the way things are going in my day, it will be quite a while before I even get a chance to eat. Part of my disability is that one side of my esophagus is a bit atrophied so it can actually take me a little bit longer to eat than most people (Jennifer).

In addition to timing their food intake, women with disabilities also discussed the importance of restricting fluids so that they did not need to use the washroom too often. The women in my study had perfected the 'art' of predicting when they would have to urinate based on what time, what type and how much fluid they drank previously.

> I definitely restrict my water at work. It's difficult because you know you should be drinking more. Either I drink and I'll pee myself and get an infection because nobody's there to help me or I'll just stay thirsty. I think it's just something that's been ingrained in me. Not so much during the day but in the night my mom basically told me that "I will take care of you during the day but I need my sleep so we need to figure out a routine that you're not going to wake me up at night." I've been trained in my bed since I was little so even that I will not wake up to go pee at night (Amy).

In all of these examples, women with physical disabilities discussed how their need to depend on others created complicated challenges with regards to eating and maintaining health. Women discussed how there was always some sort of Compromise that they were making either to their health, by restricting fluids in order to be able to time washroom breaks, or their relationships with their caregivers. This complex process was further implicated in their decision to seek support and request appropriate resources related to independent and healthy living.

Lack Of Agency And Control

Another theme that emerged with respect to depending on other people so much in their life is that of experiencing a constant lack of self-agency and control. Here, The Compromise similarly occurs when women with disabilities are forced to depend on other people and, most times, the terms of their assistance are determined by factors beyond the participant's control. These include, but are not limited to, the relationship between the staff and client, number of hours approved for service, attendant service policies on what tasks they can and cannot assist on, and the location where the assistance is needed. The majority of women I interviewed had reported that they receive fewer hours and less flexibility with those hours that they believe they need.

This feeling and the reality of lack of control in the lives of women with disabilities not only impacted their quality of life and well-being, but it also had a negative impact on their health. One participant explains how her life would be different if she had more power and control over her life and her care and support persons. She discusses the impact of constantly worrying about her food, care, and bathroom schedule. She espouses a lot of psychological and physical energy on these tasks, which leaves her feeling "drained and tired" of dealing with other aspects of her life (e.g., school, work, relationships, etc.).

> If I were able to go to the bathroom on my own, I would drink more water, which would make me essentially healthier. Or, I would feel more comfortable to eat more vegetables and stuff because I wouldn't feel like I have to hold it and feel sick. Or not be able to go pee because my attendant already left. I feel like that contributes to how I feel. If I had more independence in that area then I wouldn't worry about how much water I drank. That's why my lips are so dry because I'm so dehydrated (Carrie).

In response to this Lack Of Agency And Control, women described various ways in which they attempted to regain a sense of control. Some women spoke about how choosing to 'splurge' and eat out could also be empowering. In this scenario, treating oneself was a form of resistance to

the forced compromise of managing meal preparation with caregivers, some of whom are challenging to work with.

> Everything in my life takes planning and direction and so much work that I feel like; if I can just on the way home, buy a sub or order sushi, then, go home and eat it, it's much more satisfying then waiting for the next time I'm supposed to get assistance. When somebody else [without a physical disability] goes home, they can make their own meals right away. I have to wait, figure out what time it is, ask myself: "Did I miss it? Do I have enough time to eat what I wanted to eat? Etc." Sometimes you're just at that point where it feels like, honestly, I'd just rather send the attendant away and I'll just eat supper [take out] (Carrie).

The quote above captures the way in which women with disabilities could, in a sense, mimic how they understand that people without disabilities manage meals. By opting to disregard the additional stress associated with managing attendant care for meal prep, they are achieving control, mastery and a feeling of normalcy. If normal people come home and eat whatever they want, women with disabilities can as well, although in a different manner. Relatedly, other women were able to feel a greater connection and mastery over food and eating by achieving a sense of independence, even with paid caregivers. In this situation, a slight reframe on the definition of independence was beneficial in that a person who relied on others for all activities of daily living could still maintain a sense of agency by directing staff to assist as required.

> Being able to pick and choose myself, that was a personal growth [step]. When I moved out on my own, I started cooking. That's why I had a better relationship with food in terms of being able to work physically and to have that connection with food in terms of making it, cooking it, doing recipes and finding different things. Whereas, [previously] I'd come home and my mom would have it ready for me (Amy).

For Amy, a woman who receives 24-hour attendant care services, she was able to feel more choice and agency by directing her caregivers. It was through having paid staff, as opposed to her mother, that she was able to gain some control and feelings of pride over her eating. For women who were at the more severe end of the disordered eating spectrum, purging, restriction,

and other eating disorder behaviours were also believed to mitigate the feelings of helplessness and lack of control that can go along with disability and depending on other people.

> Around the age of 16 or 17, my mom was pregnant with my four-year-old sister. Looking back, it might have been a control thing. My mom wasn't focusing on me so much. I thought, I could control what I eat and lose weight. Losing weight felt like I was doing something good (Kelly).

It was through controlling food and eating that women felt increased empowerment, even if some of these behaviours were unhealthy or dangerous.

> Because my mom would dress me, I never really got to have any privacy. For the longest time, she didn't know about my purging. It felt good to have this secret that was mine. I liked being in control of that. I felt that I was getting back at my mom, saying to her: "Look! I'm my own person and I can take care of myself or I can make myself sick!" (Kelly).

Taken together, there were multiple ways in which women with disabilities attempted to use food and eating to increase feelings of control, self-efficacy, and mastery.

In addition to how the Lack Of Agency And Control impacted women's day-to-day routine, it also impacted their decision to seek treatment for their disordered eating. In this instance, the participant compares the lack of control experienced by her as a woman with a physical disability with the lack of control experienced by women in an eating disorder treatment centre. She explains what it is like to her to feel like she is constantly being watched and judged by other people.

> It's almost like you're under constant surveillance. Because you need help with getting the food out, there's this additional supervision that people without a disability wouldn't have. Some of the treatment programs where you have to get fed [supervised meals] are actually like that. It's extra surveillance compared to the other people (Michelle).

Interestingly, Michelle describes how she is set apart from other women with eating disorders and, at the same time, this constant surveillance is also one of the reasons that she states that she will not attend an eating disorder program. In this way, her dislike of being constantly

monitored also contributes to her resistance to traditional treatment or support for eating disorders.

Complex Cases

The second subcategory (third-level) under The Cost Of Support refers to the experiences that the majority of women interviewed had with regards to feeling like an outlier every time they interacted with the healthcare system or sought out support for healthy living (e.g., dietician, exercise programming, diet or weight-loss programs). Women with disabilities described repeated narratives where professionals and experts were at a loss in recommending specific health guidelines. Most of the participants had been told by numerous professionals that they were the "first person with a disability" that they had worked with and they were uncertain due to "a lack of research and healthcare recommendations" for this group. For persons with both a disability and an eating disorder, this experience of being a "Complex Case" was magnified. Below, one participant discusses her experience being diagnosed with an eating disorder as someone with cerebral palsy.

> People with cerebral palsy usually have a hard time maintaining their weight. Not only did I not eat properly but, naturally, my body's made smaller. It's sort of like a double whammy. It made it a lot harder than it had to be. I felt like I was weird almost because they weren't really talking about the fact that I had an eating disorder. They were scurrying around it because they couldn't know for sure. [They were talking about] weight loss and how unbelievably thin I was. That they'd never seen somebody look like I did and was still functioning (Michelle).

In the above-mentioned situation, not only did Michelle's disability shield the doctors from accurately identifying her eating disorder, but her disability also contributed to challenges while treating her eating disorder. She explained that "I take laxatives regularly because my bowels are kind of screwed up from my disability and also my eating behaviours. It's hard to tell which is which and which contributed to which problem." For Michelle, her need to use laxatives, due

to her disability, complicated her abuse of laxatives as a function of her eating disorder. In the interview, the participant described how she would often use her disability as an 'excuse' in terms of her low weight and abuse of laxatives, in addition to the fact that she did legitimately have CP that is associated with low weight and digestive issues. As a result, her treatment was complex. In the next section, I will briefly describe two different fourth-level subcategories that explore how women with physical disabilities described feeling like a "Complex Case" when they sought out medical care or other supports.

Blinders

In this first subcategory (fourth-level) under Complex Cases, I discuss the theme that emerged repeatedly in the study regarding how participants felt that their physical disability overshadowed almost all of their other support needs. For instance, Kendra explained that "With regards to my experiences with finding medical interventions or support, I find that sometimes my experience with disability is used as a master status to explain why I 'everything'". In this sense, it felt as if their identity as a woman with standard women's health needs (e.g., gynaecological health, disordered eating risk) was eradicated and the healthcare professional could only see the woman's physical disability. This was particularly true for women who struggled with disordered eating symptoms. In one woman's account, although she probably met criteria for Anorexia Nervosa at the age of 17, she was not diagnosed until she was 27 due to her low Body Mass Index being attributed to her cerebral palsy. She recalled:

> I felt like I was weird almost because they weren't really talking about the fact that I had an eating disorder they were kind of scurrying around it because they couldn't know for sure…and then I think sometimes when I was at my sickest, people thought that it was my cerebral palsy (Michelle).

Another participant, Kendra, questioned why the acid erosion on her teeth was not flagged during her university years when she struggled with frequent binge eating and purging.

> I question if I had been an able-bodied university student who had to come in with that much acid on my teeth, would they have suspected that I was purging. Also, I'm a fairly solid looking woman. I have broad shoulders, which maybe would have played into it (Kendra).

Here, Kendra suspects that the different ways (e.g., physical disability, not underweight) that she did not fit the popular narrative of a woman struggling with an eating disorder may have hindered a potential diagnosis or offers of treatment and support. In other examples, when women with physical disabilities did seek out assistance for healthy eating and/or physical activity, they felt dismissed by healthcare professionals who seemed to be overwhelmed by their potential medical complications associated with their physical disability. In the example below, the healthcare practitioner simply refused to see the participant as a client. Although it is not clear why the dietician would not see the participant, it relates to a constant feeling that all of the participants experience when seeking support or treatment – that they are too complex and difficult to treat.

> I saw a dietician once. She read my journal and she's like, "No. I can't." She said, "No, you're doing what you're supposed to be doing." I stopped there. I think that she was at a loss because she didn't know how to handle persons with disabilities, I guess (Mariam).

Alternatively, in the next example, the participant describes how she has found healthcare professionals who are willing to work with her; however, she felt like they are inadequately equipped to provide suitable care and treatment to someone with a physical disability. In the description below, she attributes this lack of appropriate support to a lack of understanding of the specific needs of a woman with a physical disability. She also comments on how professionals tend to become so focused on her disability status that they shy away from helping her, even if her questions have nothing to do with her physical disability.

> I find that they [health care professionals] are mostly clueless. They meet somebody like me and, honestly, even though they might want to help me, they are just not equipped to

> have clients with physical disabilities. I had this same experience when I went to the gym on campus. I honestly got the same reaction from the fitness instructors (Jennifer).

The frustration and hopelessness expressed by these participants in response to seeking supports for healthy living and eating was a common theme. Although the participants described specific examples where they had difficulty finding a healthcare professional to work with them or where they were provided inappropriate or ineffective support, the theme across all participants was that this happened across a variety of instances throughout their life.

Feeling Misunderstood Or "Special"

Related to the experience that women with disabilities described how healthcare practitioners were either woefully ignorant or avoided persons with disabilities as patients all together, when women did seek out treatment or support, oftentimes they would leave the interaction Feeling Misunderstood Or "Special". In this subcategory (fourth-level), I have intentionally selected the term Misunderstood because of its broad definition that encompasses a common theme in women with disabilities seeking support or treatment for healthy living. In these instances, the theme captures the experience that women had when they left interactions where they felt that some important aspect of the treatment plan was left out or dismissed, usually affiliated with their functional differences related to their disability.

The term "Special" was added to account for the experience that women with disabilities discussed that they were constantly made to feel that their health and care was specialized, unique, and not affiliated with the norm. In some cases, healthcare providers would openly explain that the client was the first client with a physical disability they had ever treated. This was the case for Michelle who was diagnosed and treated for Anorexia Nervosa.

> People always said that I would probably be the first person with disability to struggle with anorexia. I didn't like when they said that. It really bothered me. But I've never

> met anyone else that did [had anorexia and a disability] too. Although, I don't go looking so maybe there's some truth to that, I don't know…it feels lonely (Michelle).

This participant further explained how her unique status as a person with a physical disability and an eating disorder complicated treatment due to confusion around BMI recommendations.

> We've had a lot of discussion and dispute because my therapist specializes in eating disorders. I've said before that for me to get to a BMI of 20, which she thinks most people don't relapse if they make that BMI. It's really hard and I probably will never be able to maintain it. There's not a lot of research on disability and eating disorders (Michelle).

Interestingly, the belief women with disabilities feel special or unique can also support disordered eating thoughts and behaviours, such as maintaining an underweight BMI. For other participants who struggled with less severe eating and weight issues, they discussed how they completely avoided support and treatment centres that they understood to be primarily set up for the needs of able-bodied people. For instance, Amy stated "I can't go to like a fitness place because they don't know anything about neuromuscular conditions. It needs to be a really specific person that understands." Other participants who had sought out services in mainstream (i.e., not disability specific) clinics for support with eating and weight management found themselves let down and disappointed. As the example below illustrates, healthcare professionals were hesitant to supply definitive recommendations.

> A couple times they were just like, "I'm not sure about the activity level or I'm not sure how much that accounts for [the neuromuscular disorder]. That's where I'm like, "Okay, you're just not sure." Or, it's in the subtle message. She didn't seem that comfortable and that sends a message to me (Mariam).

Moreover, the misunderstanding that occurred in the above example was not only the hesitation in providing specific recommendations, but, also, the apparent discomfort and lack of confidence that the healthcare professional displayed in working with a client with a physical disability.

Consequently, many disabled women described feeling the need to rely on themselves, particularly for issues related to their body, any caregiving, their daily routine and functioning, and their health. This method of coping seemed to be in direct response to the aforementioned experience of seeking advice, counsel, research, or treatment and receiving messages of misunderstanding, confusion, and uncertainty from various medical or health experts. In the absence of the information they sought out, women with disabilities had learned to become their own experts. As Kendra explained, "Women with disabilities are left out of that conversation about food and body image."

For women interviewed, the experience of being different from traditional narrative of eating disorders and disordered eating made them constantly feel like a case study. In psychological literature, a case study is a curious and interesting clinical situation related to a single individual. The case study is so interesting because of the fact that it sometimes does not generalize to our well-established understanding of a disorder or clinical presentation. For women with physical disabilities, particularly those interviewed who had clinically significant eating disorder symptoms, their comorbid presentation of a physical disability and a eating disorder was novel and fascinating to healthcare professionals. For example, Michelle recalled how "the doctors just kept talking about how unbelievably thin I was. They said that they'd never seen somebody look like I did who was still functioning."

One of the disadvantages to being a case study for women with physical disabilities was that they described feeling that they were all alone in their struggles with eating and weight issues. Some, who sought treatment and support, were even directly told that they were unique and one-of-a-kind, like Michelle. "People always said that I would probably be the first person with disability who struggles with anorexia. It really bothers me…because it feels lonely."

Michelle also recalled some of the challenges she faced in receiving eating disorder treatment due to the lack of knowledge in this field for women with physical disabilities.

> We've had a lot of discussion and disputes. She gives recommendations based on Toronto General Hospital's Eating Disorder Clinic. For me to get to a BMI of 20, it's really hard and I probably will never be able to maintain that. When you're talking to someone with a history of anorexia, telling you that they can't maintain this weight, it's hard. (Interviewer: I guess it's like walking in the woods for both of you because you don't really know what a healthy BMI is for someone with cerebral palsy). There is not a lot of research on disability and eating disorders (Michelle).

Throughout the interview, Michelle provides additional examples of ways that she did not fit with the traditional recommendations for persons with eating disorders, such as eliminating the use of laxatives completely. For others interviewed, although they did not seek treatment, they found that the information available to them online did not quite capture the disorder presentation for women with disabilities. Kelly, for example, did not meet the stringent BMI guidelines to have a diagnosis of Anorexia Nervosa. This, in combination with her harsh self-critical voice, made it particularly challenging for her to accept that she had a problem and perhaps needed some support or at least validation.

> I always thought that I had EDNOS from what I could read online. It basically meant that you had mental thoughts or behaviours of an anorexic but didn't quite fit the guidelines. I didn't really fit anorexia because I didn't have an underweight BMI. Various things that I found online led me to think that I had a problem but I didn't want to admit that to myself. I would read it and go, "oh yeah that sounds about right." But later, I'm like: "Don't be stupid! There's nothing wrong with you. You're just being a stupid, dumb cow who's fat!" I was always constantly putting myself down (Kelly).

For the women in the study who did not meet full-criteria for an eating disorder, but rather had symptoms of disorder eating, they also felt confused and left out of the available recommendations. However, they also felt left out of the conversation of effective weight-loss strategies. Because of this, women discussed how they had developed their own guidelines and diet strategies.

> That's the really sad thing. If I want to do this, I'm going to have to figure out what works best for me. I'm going to have to create my own diet or eating habits because nobody is going to be able to really help me. As somebody with a disability, I'm already accustomed to doing that in other areas of my life where I've had to figure things out for myself. It makes you more resilient, but at the same time, sometimes it's nice to be able to talk to somebody who can guide you (Jennifer).

This was particularly relevant with regards to recommendations of daily caloric intake. Women with physical disabilities who were non-ambulatory felt that their slow metabolism and inactivity was different say from a woman who had an office job and spent many hours in a day sitting.

> I probably ate in the 800 calorie range. I don't like to eat any more than 1000 calories a day. I think that it's only 1000 calories that are needed just to keep my body alive and to maintain weight. I really wanted to lose the weight, so I just dropped it down by 200 calories (Kelly).

Each woman interviewed who had dieted through calorie restriction had her own justification or rationalization for her calorie limit. All of the women had expressed that she felt she was different from able-bodied women and that nutritional recommendations were obsolete for women with disabilities. As demonstrated in the sample quotations provided, women felt that they needed to eat much less calories than what was recommended for people without disabilities.

> I've sort of realized that if somebody suggests 1200, I should go with 1000 calories. I feel my policy has always been like, "less is more." Only because I'm so confused about what is actually appropriate. I can't remember who told me this but apparently somebody, a professional doctor, had been wandering around saying 600 is how much people that are sitting all the time should be eating and I thought that was a ridiculously low (Mariam).

> I wouldn't eat carbs. I would literally try to stick to eating under 1200 calories (Carrie).

> I have had naturopaths or other doctors that have asked me to record my diet for a number of weeks. When I do, they believe that I am not eating enough calories. He wanted me to add another 800 calories. I feel like I eat enough. I don't feel like I could fit more food into my diet on a regular basis (Hannah).

Taken together, feeling set apart from clinical guidelines, most women with physical disabilities responded by independently creating the guidelines that they felt worked best for them. However, for many of these women, that meant restricting to very low calorie counts to compensate for their lack of physical activity and their sedentary lifestyle.

Disempowered

The next subcategory (third-level) under The Cost Of Support refers to the experience of women with disabilities in which they described losing all hope and faith in receiving appropriate supports and ultimately, achieving their ultimate level of health. In other words, after a lifetime of difficult medical appointments, unhelpful doctors with limited training and inaccessible treatment, the women interviewed described feeling completely disempowered, fed up with the medical system and finished with constant efforts to improve their health. These feelings, in turn, affected eating and weight-related behaviours. For instance, below Hannah describes a situation that was common among the participants. She explains that her doctor's insistence that she lose weight causes her to feel increased shame and guilt. As a result, she engages in binge eating after appointment and she avoids seeing her doctor when she experiences disability-related chronic pain and inflammation.

> I feel really bad. I'm positive that it's probably led me to eat sometimes after appointments. But, it also makes me avoid things. I will avoid going to my doctor to tell him that I am having an inflammation because I know what I'm going to go through (Hannah).

Similarly, Amy recalls how a lifetime of being told by her doctor to lose weight contributed to more disordered eating and increased shame that she did not lose the weight she 'should have'.

> I just remember fear when the appointments came. I remember thinking, "Oh! It's two days. Let me starve myself and then maybe I'll lose the weight that I know they're going to tell me that I put on" but I'd never do that for very long (Amy).

This medical and health disempowerment was not limited to women in the study who were advised to lose weight, rather it seemed to be a common theme amongst all of the disabled women. This first participant discussed how she stopped going to her doctor unless absolutely necessary due to the repeated feeling and experience that it does not improve her prognosis and it contributes to her low mood.

> The doctors would check my leg reflexes by banging on my knee and that was quite frustrating. They would make me do leg exercises and ankle exercises and various things like that over and over every year. Considering that I haven't really changed too much in the progression of my condition, it really wasn't needed (Kelly).

Other participants spoke about their avoidance of the doctor's office or hospitals in general, even if they knew it was important to go.

> I haven't really been in a hospital environment. I try to avoid it as much as possible. Even when I am sick, I try all the do-it-yourself in home things before I can even go to the hospital. It has made me more wary. Because you are prodded and poked you can't do anything because they are trying to help you (Jess).

Of particular note was Jess's final comment. She discusses how invasive and painful her experiences are with medical doctors; however, she notes that, as a patient, you have to endure this negative experience because the doctors "are trying to help you". The power imbalance between patients and doctors makes it significantly more difficult to advocate or voice concerns because the distress or trauma is endured under the perception of medical care. As a result, most participants were highly avoidant of healthcare professionals and doctors. Unfortunately, the feeling of disempowerment seems to have generalized for most of the women interviewed in terms of their hope for change in services for the future, including support for disordered eating and healthy lifestyle management. "Unfortunately, that's how they are trained, that's what they are taught. They don't think they are doing anything wrong" (Jennifer).

Furthermore, in response to feeling disempowered in terms of health management, nearly all of the participants described relying on themselves for their healthcare needs. The quote below, by Kelly, captures the experience of relying on Google and knowledge of her body prior to seeking medical help.

> I'm so sick of going to the hospital or going and seeing doctors all the time. If I need to know something, I just Google it. If the thing that I'm looking up sounds about right and I can deal with it without having to see a doctor, then I'll do that. Unless it sounds like it's going to be something serious, then I'll see a doctor. I'm usually pretty good at knowing my own body. If something truly doesn't feel right, then I'll go to the doctors. I'm not going to the doctors every time I get a cold. I don't want to keep taking medication for something that can go away on its own (Kelly).

Like many other women in the study, Kelly carefully weighs out the potential costs of visiting the doctor. In most cases, she refuses to see a doctor unless she believes it could be something more "serious". Further, Kelly believes that she is an expert in her own body and when something could be seriously wrong with her health. Other participants talked about the similar necessity that they adopt the role as the expert in their healthcare. First of all, many of the women interviewed discussed how they had multiple doctors and specialists at different times in their lives. As a result, they were forced to be the organizers and managers of their healthcare and their treatment. Secondly, many of the participants were repeatedly treated and, in some cases, told by different healthcare professionals that they were a special or unique case. As mentioned in the previous section, women were treated as complex cases that did not conform to typical medical guidelines or treatment protocols.

Barriers To Healthy Living Support

The last third-level subcategory under The Cost Of Support explores the theme of encountering numerous barriers in finding appropriate help and support that was described in all of the women's interviews. In this scenario, barriers refer to all those impediments that exist

that can prevent or obstruct the women from receiving support. Although barriers can include uneducated or ignorant attitudes of support workers, this category was selected to emphasize the role of environmental and financial barriers often associated with accommodating their functional differences for disabled women. For women with disabilities, their path to healthy living was bombarded with barriers. Their bodies, which functioned and moved differently than other people, seemed to experience many difficulties being supported and accommodated. Particularly for healthy living supports, women found that they were frequently denied services due to lack of accessible transportation, adaptive equipment and non-knowledgeable staff persons.

> It's frustrating because in all of Toronto, I think Variety Village is the only accessible gym. It's a whole like 4 hours to go to the gym for like an hour. Then there's swimming, which there's only one barrier-free program that I'm aware of. You have to be out-of-work to be able to go swimming. There's personal attendant care in that program. I tried paying for a personal support worker privately. The costs are so high that I don't know how you're supposed to do that. It's definitely a horrible, horrible, horrible mess (Mariam).

Financial barriers were a common issue for almost all of the participants. Even those who did have adequate finances, navigating an inaccessible environment for achieving some sort of health and fitness meant needing funds above and beyond what persons without disabilities require. What becomes evident from the research participants experiences is that seeking appropriate support services for healthy living is an exhausting task. It requires not only a great deal of physical energy, but also emotional energy that contributes to feelings of powerlessness. As Carrie expressed:

> Everything in my life takes planning and direction and so much work that I feel like; if I can just on the way home, buy a sub or order sushi, then, go home and eat it, it's much more satisfying then waiting for the next time I'm supposed to get assistance. When somebody else [without a physical disability] goes home, they can make their own meals right away. I have to wait, figure out what time it is, ask myself: "Did I miss it? Do I have enough time to eat what I wanted to eat? Etc." Sometimes you're just at that

> point where it feels like, honestly, I'd just rather send the attendant away and I'll just eat supper [take out] (Carrie).

Ultimately, because of these multiple barriers related to environmental barriers, managing personal support workers, finances, and accessible transportation, Carrie explains how her healthy living suffers. Nearly every participant had a similar story of frustration involving a lot of emotional investment that they each coped with in different ways. For some, it was demoralizing and for others, it could be motivating in that they would seek out fully accessible supports and services. Take together, there was a strong sense of anger at the injustice of having to deal with all these additional barriers and obstacles to find health, physical activity, and other supports.

Embodiment Differences

The second first-level subcategory refers to differences in appearance and embodiment of the participants relative to non-disabled women. The term embodiment was chosen, as opposed to appearance or body image, namely because embodiment captures not only the individual's feelings connected to her body and physical appearance, but also the broader definition of how women's bodies exist in physical spaces and how they interact with the environment. Further, embodiment captures the feelings and interactions within a sociocultural context between a woman's body and her experiences with its functioning, pain, mobility, etc. This subcategory summarizes how embodiment experiences differ from the norm for women with disabilities, particularly in terms of feelings of attractiveness, desirability, and normality. The examples provided that follow capture differences in how a woman with a disability's body is perceived and evaluated, usually negatively, by others. Within this category, a theme that emerges is, again, the normalization and idealization of thin and able-bodied bodies as the standard of beauty. Participants discussed the difficulties experienced when they felt that their bodies were considered unattractive in various areas of their life including by potential intimate partners, media, health care professionals, and also by their own self-imposed standards of beauty.

Body Esteem

The first second-level subcategory under Embodiment Differences is Body Esteem, which refers to the feelings and judgments about one's body or appearance. For women with disabilities, their body esteem was complicated by social, psychological and cultural factors. All of the women interviewed had described an unequivocal understanding that their disabled bodies were not viewed as attractive and beautiful by traditional societal standards. Rather, they

spoke about the preferences in society for thin, fit, and healthy bodies. As Jennifer explains, "No matter what I do, I'm not going to look like somebody who is able-bodied and who is fit and who eats well. I'll never look like that." In a world where those aforementioned attributes are the ideal in the measurement for attractive, women with physical disabilities felt as if they weren't even close to being considered on that scale. Besides the fact that they have a disability, women interviewed spoke of specific ways in which they thought of their bodies as unattractive or not normal.

> I feel like fundamentally I will never be understood as conventionally attractive or be the beautiful [model] that sells cars. I really want to be that comodifiable beauty as opposed to like a spiritual beauty [being beautiful on the inside] (Kendra).

The category, Body Esteem, was further broken down into two subcategories (third-level) that captured what most contributed to the Embodiment Differences experienced by women with disabilities, named Comparison To The Norm and Body Nitpicking And Checking.

Comparison To The Norm

Comparison To The Norm refers to the ways in which women with disabilities' bodies are constantly compared to what is understood as "normal". This normal represented bodies without disabilities, healthy bodies, fit bodies, and thin bodies. Symmetrical bodies that are free of damage, scars and other abnormalities and eccentricities. For most women without disabilities, there is a constant comparison, and eventual disappointment, to a modelesque-type woman who resembles a Barbie doll. However, for women with disabilities, the bar of comparison was set differently. The participants discussed how 'the measurement of success' in terms of physical appearance was how they compared to "average" women without disabilities with the final goal being to look "normal". Some of the physical features that women in the study wished to change in order to appear more attractive were secondary effects from their

disability. “Fixing” these aspects of their appearance would primarily serve to make them look less “disabled”. In this first quote, Kendra explains what she would like to change about her body to improve her Body Esteem.

> Part of the cerebral palsy is that I had a brain haemorrhage when I was little and it caused my eyes to cross. They've done 7 or 8 surgeries when I was younger to make my eyes as parallel as possible but one of them is still lazy. I would really like to fix that and I need about $8000 of orthodontic work to make my smile completely symmetrical. It’s not awful but it’s not symmetrical. If I was going to change anything, I’d want abs and I’d want my face to be really symmetrical (Kendra).

In addition to wanting to correct the physical manifestations of her disability, Kendra also joked that she would like a more toned stomach. Throughout the interviews, the women would compare not just their appearance to nondisabled women, but also their weight and size.

> If I saw someone walking by me, I would always compare. My thing has always been my arms are big so I always compare my arms. I was really, really small then but I would still find some fault in how I was looking (Kelly).

> I just thought in terms of how I should look. I would very much like to not have a belly. That was mostly the area of concern, I think for everybody that age. Big butts have always been in, but it should be big and shapely, not big and saggy. Not having a double chin, or a very large face. That was definitely how I would gauge. How do I look in comparison to these other girls (Jennifer).

Each of the women used the comparison of similar age peers without disabilities in determining their own beauty and body esteem. The participants further discussed how they were also compared to other able-bodied women by other people in their lives (e.g., family, friends, PSWs). In the next quote, Carrie explains how her personal attendants frequently compare her to her able-bodied friends, insinuating that she is not as pretty as them. She states “I’ll be like, ‘Oh my God! I don’t look great in this.’ They [the attendants] will be like, ‘Well, I’m sure your friend doesn’t have those problems,’ or ‘Oh, your friends have perfect bodies. They’re so skinny or pretty.’” When asked how she feels when her attendants compare her to her able-bodied friends, Carrie responded that: “It makes me feel like I will never have a

normal body." Here, being thin and attractive is reserved for those without disabilities. For other women interviewed, they expressed uncertainty as to whether or not they could ever achieve the 'thin' standard reserved mostly for women without disabilities. In the quote below, the participant explains that although she recognizes that her larger stomach can be attributed to her disability, she also does not want to make excuses for herself.

> I have scoliosis that does make me appear to be larger. Even though I've had the spinal surgery, my spine is still curved and that does make me appear to be larger than I actually am. That does affect me. [Although] when you see models or celebrities sitting down, they obviously have a flat stomach and I'm like "well, why don't I have that?" A part of me knows that it is photoshopped but at the same time, if they can look have a flat stomach sitting down then my disability isn't the cause for why I have such a fat stomach (Jennifer).

In all of these examples, women with physical disabilities were negatively impacted by comparing their bodies to those of women without disabilities. Each of the women understood that being attractive and beautiful meant that they should look as similar as possible to the attractive women without disabilities.

> It's always been comparing myself to my able-bodied counter parts. I would say that the vast majority of my friends and family are all able-bodied. So because that's what I've been surrounded by my whole life, that's what I aspire to. It's that comparison that makes me feel like a less-than-desirable woman because of my disability (Jennifer).

> There's got to be something intellectually violent about comparing yourself to someone who walks all the time and who doesn't have the same sort of body composition (Kendra)

Physical disability and body differences are not viewed as attractive or beautiful and the women in the study had learned this about their bodies as early as puberty. Women who were surrounded by peers and other women without disabilities seemed to be particularly sensitive to this embodiment difference. Many of the women interviewed had internalized the message that beauty exists only outside of disabled bodies. On the other hand, some women did discuss

comparing themselves to other women with disabilities. For one participant, this comparison proved to be just as damaging to her body esteem.

> I was playing basketball at a really elite level. Many of the women who played wheelchair basketball, whether it was like inflated in my mind, are just beautiful, like Barbie in wheelchairs, and I didn't feel like that (Kendra).

Here, Kendra suggests that even amongst those in the disability community, there is a hierarchy of physical attractiveness for women, with those possessing traditionally attractive qualities found in able-bodied women (e.g., thin, beautiful, blond) being at the top.

In response to feelings of being inadequate and unattractive, nearly all of the participants endorsed using various tactics to compensate for their physical disability and align themselves closer to the able-bodied ideal. The term compensation as used here captures the experience of women who made up for the perceived negative attributes associated with their physical disability by enhancing another personal characteristic of their lives that they have the power to control. In other words, women made themselves more valuable in some way by compensating for their disability. The metaphor alluded in this instance was that of a balance scale where a woman's disability weighed down her value so she uses other characteristics, such as weight and appearance, to balance out her net social value. For instance, Jess states how "a lot of my diet is always tied into trying to look nice despite being disabled." In many cases, women felt that compensation was not solely a psychological attempt to increase their self-esteem, but rather it was an adaptive and necessary skill that helped them survive and thrive in an environment that does not accommodate physical differences or disabilities.

> A lot of the time, like with my appearance, you try to over-compensate. You spend that much more time on your make-up and picking out what you are going to wear. All of these things are so much more effort just to even approximate what you want to look like or how you want other people to see you (Jennifer).

For some, this message of having to compensate for their physical disability was first introduced by their families.

> I got my first prosthetic when I was 6 months old. It wasn't even my choice, [rather] it was my parents'. They got it made [custom]. It was a hassle more than anything because it was so slow. They're imitations and not like a normal hand. I've always gotten along better without the hand. If it were up to me, it's just more comfortable without it. I just wear the prosthetic for cosmetic reasons. [The prosthetic at six-months-old had no functional value?] No, not at all! Not when you're six-months-old because it didn't even bend at the elbow. It wasn't like I could use it for crawling or anything like that (Heather).

For Heather, her family's need for her to look normal had overridden her mobility and any functional advantages that having or not having a prosthetic could possibly bring. Heather's ability to crawl was actually hindered by her prosthetic. Further, it sent her the message that missing a limb was not acceptable and it was something that needed to be fixed. Similarly, Emily felt desperate to fix and hide both her chin and her fingers that were physical manifestations of her disability.

> I was probably showing my cleavage to hide my fingers. For me, there was kind of a direct link…[What are some other things you did to hide your disability?] Not wear skirts. Longer hair to hide my profile and my dumb chin. Before that phase, there was a phase that I was wearing long sleeves to, again, hide my fingers (Emily).

For others, there was less of a need to hide their disability and more a push to elicit a positive opinion from others by enhancing other qualities (i.e., "Dress to Impress"). This may include dressing in professional looking clothes or carefully creating a certain look/appearance. In other words, participants understood that in some ways, "you're in charge of how people perceive you" (Heather).

Women interviewed further described how they almost felt obligated to make themselves as attractive and admired as possible because they needed to compensate that much more for their disability. Using a metaphor of playing cards, the women already felt that they

were playing with a ‘bad hand’ (i.e., disabled); therefore, they needed to ensure that they emphasized those cards in their hand that were ‘good’.

> If I'm skinny and pretty and I've been told that I have a good personality and if I have all those things going for me, I feel like I’d be able to find somebody that would look past my disability (Kelly).

As Kelly describes above, the ultimate goal of the strategy of Dress To Impress is to enhance a person’s other qualities (outside of disability) so much so that other people are able to ‘look past’ their disability and view them as attractive and desirable. To accomplish this, many women become overly concerned with their appearance and weight.

> I can’t control that I was born this way. I can’t control that my spine went crooked, my hips are messed, my feet are crooked, and that my leg is swollen. But, I can control what I wear to make myself look thinner. I can control what I eat. I don’t want anyone to ever have to look at me and think that I’m ugly. They might judge me automatically because I’m in a wheelchair but I don’t ever want to be judged because people think I am ugly. It [then] becomes my fault (Carrie).

As Carrie highlighted above, people in the world already unfairly judge disability and disabled people. Therefore, women feel obligated to do what they can to minimize the impact of disability on others’ perceptions and opinions.

The other way that women with disabilities made efforts to compensate for their physical disability was by losing weight. For example, Heather described how, “I was so sick of it. I was like I could change this. I don't have to be the ugly one. I don’t have to be the chubby one anymore. I could do something to fix that.” Not only was weight loss perceived as beneficial, but it was also understood as achievable. It was a goal that women believed they could accomplish, which was a powerful message for many, particularly for those who described being unable to change the physical impairments related to their disability.

> It was about proving it to myself. I don’t want the first impression to be like, “oh, she can't do things for herself.” I was controlling my eating and restricting and creating the

> body that I want. Basically, that's what it is. It's manipulating how you want yourself to look (Heather).

Becoming thin, which is socially desirable and admirable, can be understood as a way to distance women from qualities associated with physical disability that are deemed undesirable and unattractive. Therefore, women can become less disabled by becoming thin and attractive. Mariam captures this sentiment when explaining, "I think it's almost like this need to feel accepted and I felt like that was the only way that I'd be accepted was by having a body of a certain frame." Becoming thin and attractive also felt like an obtainable goal for many of the women. Whereas fixing one's disability cannot occur, there is a belief and societal pressure that people are in control of their weight.

> Disability is not something that you choose. Disability is not something that necessarily has a positive reputation in society. If guys aren't going to look at me because of this [my disability], then at least I'll be thin and that's when I started doing my hair and started doing my makeup when I was 12 (Heather).

Although all of the women, on some level, seemed to understand that weight loss was not a magic cure-all that would make everything in their life better, they noted that there was still a part of them that believed otherwise and motivated continued weight loss.

> I also use it as even more motivation to try to lose weight. In a lot of ways, my own goals for my body are very unrealistic. Even if I do lose weight, my stomach will never be toned like that of my able-bodied friends, an actor's or a model's. I'll never really have that physique. It doesn't really matter how much weight I lose because I am not going to look like that. But that doesn't really register emotionally. Emotionally, it's just like, "But if I could just lose ten pounds, maybe I could put that dress on and not look ugly, you know?" (Jennifer).

Furthermore, there was an awareness that, at least in the short-term, weight loss did contribute to feelings of increased confidence and self-esteem. For many women with disabilities, who had little to no control over many aspects of their lives, weight loss offered a tempting solution. Weight loss also represented hope for the future as it was empowering and achievable.

In a weight-obsessed culture, women with disabilities have attempted to compensate for their perceived negative attributes (e.g., their physical disability) by exacting control over other aspects of the appearance (e.g., weight) that would grant them social acceptance, culturally-defined attractiveness, and an avenue for social admiration. Alternately, accepting their physical disability proved to be extremely helpful in accepting their body image. However, for many of the participants, acceptance of disability in a culture that values 'normal' bodies was an ongoing journey.

> Because I've gradually found things about myself that I've found beautiful and, in return, other people have found things about me to be beautiful. That, for me, has been one of the biggest positive things in my life. That connection to my self-acceptance. If you can accept your body (Amy).

Similarly, Heather gradually became more accepting as herself as a person with a disability as she learns more about what her body can achieve as opposed to focusing on what is limiting about her body.

> Even with the disability, look what I can do. I can get muscles. I can work my body in ways that are not harmful or obsessive. Then around college, I started playing the guitar, too. I still think that's one of those defining moments for me because it was when I decided I'm going to be comfortable with who I am. I'm learning to like the way I look. I'm learning to see that I can do a lot more than I thought I could. It's very empowering when it was me finally saying, "Okay! This is who I am and I'm cool with it. Yes, I have a disability. Yes, I'm working on my eating issues. But I'm also where I am and I'm cool with that." (Heather).

Here, body acceptance represents accepting disability and resisting comparisons to the norm. In that, women have come to a place where they believe that their disabled bodies have value, beauty and deserve to occupy social spaces. This is in direct contrast to the idea that women with disabilities are beautiful despite their disability or that they are "too pretty to be in a wheelchair" (Carrie), as if disability and beauty cannot simultaneously exist. For many, that meant finding value in difference from mainstream media ideals of beauty. In the next quote,

Mariam speaks about how counting herself as apart of beauty standards helps her to accept herself and her disabled body. She states, "I think that it's almost been a protective variable in that it protects me from that unhealthy attitude…I think that part of it is that you just don't count yourself as part of normal society." Body acceptance for women with disabilities in the face of negative messages is in itself an act of resistance. Further, women discussed how practicing self- and body-acceptance is an ongoing effort that involves challenging body norms and tolerating aspects of their physical impairments that can be frustrating, painful and, at times, isolating.

In the next description of the category Body Esteem, I will explore how the thoughts and behaviours related to Body Nitpicking impacts the embodiment and body image of women with disabilities.

Body Nitpicking

This subcategory (third-level) refers to the experience of women with physical disabilities who criticize their own bodies. In these instances, the women were not comparing themselves to other women, but rather were highly critical of their own certain physical characteristics. In this situation, women with disabilities tended to be particularly critical of aspects of their appearance that were associated with their physical disability, which were viewed as a characteristic that sets them apart from their ideal beauty standard.

> I look horrible…I look really bad. I think it was even when I had been skinny or smaller, I was still nitpicking at my body. I always thought my stomach could be smaller. If I saw someone walking by me, I would always compare. My thing has always been my arms are big. I always compared my arms. I was really, really small then but I would still find some fault in how I was looking (Jess).

> I don't like my body. I don't like my scars. I don't like my feet. I don't like that the bone sticks out of [my spine] and I look like I'm the 'Hunchback of Notre Dame'. I don't like my feet because they are crooked and swollen (Carrie).

As mentioned previously, participants tended to equate physical characteristics related to their disability as less attractive. They spoke about their perceived flaws with a very matter-of-fact manner. It was unclear as to where these perceptions originated; however, participants did express that they believed that other people would find their bodies unattractive. For example, Carrie describes, "My scar can freak anybody out, so people who are not used to that sort of thing may judge it harsher than it needs to be."

Further, the women interviewed were particularly critical of their bodies when discussing issues of weight and shape. Women spoke about how having a physical disability contributed to greater body dissatisfaction because often it made them seem larger than they would otherwise be without a disability.

> I feel like either my back is arching forward and so my belly is sticking forward more. But then, I'm having trouble breathing so I'm leaning back more, which makes my belly even bigger (Amy).
>
> I'm crooked so that doesn't help the tummy area. My spinal cord is crooked so it makes me look lopsided and the additional fat makes me look even more lopsided. I just look ugly. Like I look crooked (Carrie).
>
> I have a scoliosis and sometimes you kind of look lopsided. You tend to struggle with that because you don't fit it into that ideal anymore (Mariam).

Women interviewed were particularly critical of their stomach area. Here, excess fat and disability characteristics were painted in the same critical brush of being unattractive. Often women blamed their disability for what they perceived as abnormalities that contributed to a greater perception of fat. The impact of the disability seemed to contribute to longstanding body dissatisfaction in areas of their body that they tend to critique or dislike. There was a strong association between beauty and being symmetrical (or not crooked or lopsided). Alternatively, for other women, they believed that they would be critical or dissatisfied about their body regardless of their size or their disability status.

> I was looking at myself and thinking I look really bad. I think it was even when I had been skinny or smaller I was still nitpicking at my body. I was always like oh my stomach could be bigger, smaller or [so on] (Kelly).

Being critical of one's body can be harmful to any woman; however, when the criticism echoes those in a society that devalues disability and difference, it can be particularly deleterious in terms of finding self-acceptance for women with disabilities.

Some of the women explained that they were eventually able to get to a place where they reduced the amount of targeted criticism on their bodies. For many, they were able to get to a place of body tolerance, even with a disability. However, first, they had to accept that they were disabled.

> I always had thought that I would eventually be an adult without a disability. Whenever I looked at myself in the future, I would be a different person all together. When I recognized that my disability was permanent, then I started that journey and the ups-and-downs that came with that journey (Amy).

> I did dream of a prosthetic that looked really real and wasn't like stiff and awkward. But, once I realized that this is me. This is how it's going to be. I think it was okay. It takes time (Heather).

Tolerating one's body represents not actively hating one's body or not constantly wishing for a different body. It does not, however, mean that the woman loves or celebrates her body as encouraged by current body positivity movements. In the first quote, Amy discusses how she arrived to a place where she better accepted her body.

> A place where I didn't accept my body or, not even so much that I hated it but, I wished my body would be different. I don't want to do that anymore because it took me a long time to feel comfortable in my body. When I have those emotions, I say like, "okay, this is what it is. I don't have to necessarily love it because it does have a negative component to my health, as well. It's not just a pimple where it's not going to affect my day-to-day life. But, for me to do that on a daily basis is like betraying my body because we worked together for so long. It doesn't mean that I never say those things to myself or I don't feel that way sometimes. But, I don't want to do that. I'm not going to do that (Amy).

Women felt accepting of their bodies, even though they did not necessarily like them all the time. A common example was in regards to accepting physical impairments, chronic pain/fatigue and reduced mobility.

> I'm okay with my body in terms of a person with a disability. I've accepted and learned to love it. But, the changes that the disability is making to my body I don't necessarily like. For example, the scoliosis is pushing my back even further. Those are things that I'm having to accept (Amy).

For women with physical disabilities, body acceptance also included external objects, such as mobility devices and prostheses. These objects were just as much a part of their embodied existence as their disabled bodies. Women discussed how they experienced both positive and negative feelings towards their devices with regards to how they related to their appearance and identity as a disabled woman.

> I no longer feel so bad about taking it off. I'm totally comfortable without it too and I type without it so I leave it in my lap at work and it's totally fine. I still find it hard to do without people looking at you. That's something I'm working on (Heather).

For many in the study, the promotion of body love and body positivity in mainstream media did not adequately capture their experience. At times, their bodies were the source of immense frustration and pain. Women with eating disorders in the study also discussed how the goal for them was to exist with their bodies without efforts to hurt or destroy their bodies through self-harm or disordered eating behaviours.

> I am heading towards my journey to recovery. I was actually binge eating and gaining weight. I couldn't control it. No matter how much I tried, I couldn't go back to not eating or restrictive eating. I started seeing my counsellor again. Once I was on medication, I couldn't hear that voice in my head that was telling me: "You're fat! You shouldn't eat that! Stop eating fatty!" - all the really negative comments that I would hear in my head all the time. I finally didn't feel exhausted and I finally started to gain some confidence and make friends. I started just living, I guess, a normal life as a teenager (Kelly).

As Kelly describes above, coming to peace with her body did not mean that she 'loved' her body. In fact, she didn't appear to even like her body that much. However, she was able to stop

self-destructive behaviours. Further, by seeking support and taking medication, she was able to decrease that self-critical voice in her head that promoted self-hate and harmful behaviours.

The "Spoiled" Fruit

The second subcategory (second-level) subsumed under Embodiment Differences was labelled as The Spoiled Fruit. This category was created in recognition of the role that relationships played in determining the women's embodiment and body esteem. The women described how the ways in which other people responded to their bodies contributed to their feelings towards their bodies. As women with physical disabilities, they had received the message from a very young age that their bodies were not attractive, sexual, or normal. Further, the women had also expressed that they understood themselves to be less than ideal spouses, wives, partners, and even friends. They discussed how these messages impacted their relationships and self-esteem through avoidance or overcompensation in romantic relationships. "Spoiled Fruit" was a metaphor described by many of the participants. It refers to the perception of disabled women that they are undesirable partners and romantic interests. The metaphor was chosen as a representation that women with disabilities as being the lowest fruit on a fruit tree. In this metaphor, the Spoiled Fruit is usually bruised or damaged in some way.

> I tend to think of myself as a low hanging fruit. Recently, I went to go see a local artist who has like a pretty good [fan] following. It was really interesting because everyone was fawning over this man and I just hung back because I kept thinking there are literally 80 women in this bar and they're all beautiful, like the type of women that start bar fights and stop traffic. It's just going to look silly if I hit on him (Kendra).

Similar to Kendra, women interviewed tended to compare themselves to other women without physical disabilities. In this category, disabled women tended to use romantic interest as a marker of attractiveness, desirability and 'success'. It was important to women that other people view them as 'dateable'. Some women spoke about the frustrations that they experience when

they are seldom considered to be matched or set up by their friends or family with potential partners or romantic interests. In these instances, women interviewed used these as further proof that they are undesirable or undateable. Carrie explains how "all my friends would go out and they would all get attention, which still happens, and I don't." Relationships and sexuality were also a very important factor in determining how women with disabilities felt different and less desirable because they served as either confirmation or disconfirmation of a widely held and powerful belief. For Mariam, these messages contributed to her decision to not date or form romantic relationships.

> I feel like messages that I get about disability and a disabled person, in general, is an undesirable person. In my mind, I think that's part of the reason that I can't date. I try to fight against that part of me because I feel like that's an unhealthy attitude (Mariam).

For Mariam, although she intuitively understands that believing herself to be 'undesirable' is unhealthy and likely contributes even more so to her status as a single woman, she still cannot shake the unhelpful belief. Interestingly, even in the context of disconfirming evidence or high self-esteem, women still felt surprised or confused if a person expressed any romantic interest in them.

> I went directly from eighth grade to an all girls' school for four years. So, I was very sheltered and I didn't have a lot of guy friends. It wasn't until college when I noticed that people started asking me out and I was completely shocked at first. I was like "oh my goodness, I can be attractive to someone!" (Heather).

In addition to being undesirable due to their disability, women interviewed spoke about the additional impact of excess weight on their dating prospects. As mentioned previously, excess weight is viewed as disabling and unhealthy, particularly on an already physically disabled body. The impact of excess weight in terms of body esteem and perceived attractiveness to potential romantic interests is equally devastating. Women interviewed spoke of their own distaste for fat bodies. For example, as Kelly describes, "I've seen pictures of really obese

women on the Internet in wheelchairs and I never wanted to look like that because that's just repulsive." Further, participants spoke about how having excess fat or weight would decrease the chances that they would find a romantic partner or someone to love them. As described below, women with disabilities are already dealing with a small proportion of interested lovers. To add another undesirable physical appearance trait, such as fat or excess weight, would most certainly seal their fate as being undateable.

> More like who is going to love a fat disabled person. It's bad enough that I'm in a wheelchair, it would be nice if I had a nice body to go with my pretty face. If I'm fat, someone has to get over two things. They have to get over the fact that I'm disabled and then get over the fact that I'm chunky. And I feel like if they only have to get over the disabled part and can still look at my body and be like, "Oh my God! It's so attractive," then I'm okay (Carrie).

In this quote, the participant discusses how difficult it would be for a person or potential romantic interest to look past her perceived faults, referring to both her physical disability and her excess weight. Perhaps intentionally, Carrie refers to her body as an "It" in the last line of her quote. This seems to capture the experience women with physical disabilities express that in terms of relationships, they are reduced to a list of faults and assets that sum to their dating or romantic partner potential. In this equation, traits related to their physical disability are always seen as a deficit.

> I've given up the idea that it's even possible. My sister was trying to convince me to do online dating. If you meet the person and then they're like: "Oh no! I ended up with a fluke. This person is disabled." Or even if you put that you are disabled, it might drive whatever potential person away.

Feeling unattractive and undateable across many different situations contributed to not only a feeling of low body-esteem, but also efforts to ameliorate these perceived disadvantages through passing as normal and disordered eating.

> Hypothetically, if I had a date with a stranger, I probably wouldn't bring my wheelchair. I am not there, yet. My perception of non-disabled people is that they are closed to the

> idea of dating a person with disabilities. I've lived my life to try to hide my disability as much as possible so that people would consider me as datable (Emily).

In terms of disordered eating, there was a sense amongst nearly all of the participants that controlling their weight, an aspect of their appearance they felt they actually could control as opposed to their disability, increased the chances of them receiving attention from the opposite sex.

> I thought that it would help if I made it so that the guys wanted to be with me. I started putting on make-up, caring about the kinds of clothes I wear, and worrying about my weight. These are all things that were within my control, to make myself more like appealing and desirable. Not just to the guys but also to other girls who cared a lot about their appearance and wanting to be accepted into that social sphere (Jennifer).

> When I was in college, I started noticing the male glance. I was picking up on how they were looking at me. I grew very obsessive with my makeup, my hair, how I dressed, and what I did. There's something so satisfying in having these guys look at you in a way that said they wanted you. It was very different for me and it was not something that I was used to. It was very reinforcing that I'm not defined by my disability, that I am wanted (Heather).

For a few participants, they pushed themselves to become objects of the male gaze or in some ways, hypersexual. Women discussed how being sexually objectified, as opposed to objectified in other ways common for disabled people, assisted them in feeling less shame about their disability and about who they were as disabled women. Emily explained that "I even objectified myself with men. I met a lot of men through the Internet for one-night-stands and things like that. Even my body became a sexual object to fill that void." As Emily describes, sexual objectification helped her to fill an unmet psychological need related to her self-esteem. Other women spoke about similarly trying to be simply noticed and acknowledged as desirable helped them to feel less invisible and more like a 'normal' woman. As Kendra explains "Disabled women can use beauty subversively as a way to make the hypothetical third party or the hegemonic gaze understand them as human or understand them as sexual beings." She further

discussed how she oftentimes will wear low-cut shirts or flirt with men as a way to challenge the asexuality stereotype. Although some of the women discussed using their sexuality as a tool to challenge stereotypes of asexuality and attract a partner, other women in the study felt that they almost had to engage in these acts (e.g., dieting, wearing revealing clothing, makeup, etc.) to make themselves appear desirable and sexual. For instance, Heather explains how: "It wasn't ever a vanity thing. It was more a worry that I have to do this or else I would be resigning myself to what everyone assumes is that asexual person with a disability." Regardless of the motivation, all women interviewed were concerned about being perceived as undesirable and asexual. Engaging in sexual behaviours and/or finding their sexual identity was for many an empowering way to resist the insidious societal stereotypes of child-like asexuality.

Media Messages

The third subcategory (second-level) under Embodiment Differences discusses the role of the media representation in the development and maintenance of embodiment differences in women with physical disabilities. This category was split into two third-level subcategories: Left Out and Unobtainable Goals Of The Ideal Body, which captures the two ways in which women with disabilities felt that Media Messages impacted their body esteem and embodiment differences in comparison to women without disabilities. The biggest complaint of women with disabilities in terms of media representation was the fact that they were not represented at all. All of the women interviewed discussed the impact of growing up without any role model or empowering look or style to emulate. This was one of the reasons expressed why women with disabilities were so critical of their bodies and their disability. The message they interpreted was that visible representations of disability were almost always unattractive and undesirable. Further, the only way that a woman with a disability could find a dating partner and/or be

considered beautiful was if their partner was able to look past their disability (or faults) and notice other culturally-defined assets as defined by the media (thin, pretty face, etc.).

Left Out

The first third-level subcategory under Media Messages captures the experience of disability and disabled bodies being invisible or completely left out in the representation of women in media (e.g., television, magazines, fashion). Women spoke mostly about the psychological impact of not seeing someone like them in virtually any representations. They discussed how it made them feel like their bodies were not good enough and that they were so far away from the norm that they weren't even mentioned, so-to-speak, within the conversation. Below, Kendra discusses how disabled women are excluded from the conversation about body image and eating disorders, highlighting how being left out of representations of beauty can perpetuate notions that disabled women are not concerned by issues of appearance or weight.

> I find it interesting that there's a cultural assumption that women with disabilities are left out of that conversation about food and body image. I'd really like to see more examples of disabled bodies in the mainstream just to even see representations of disability in the media. I think it would give a little bit more grounding or solace to a sense of normalcy or a common space (Kendra).

Similarly, in the next quote, Jess describes how media and other representations of beauty have shaped her distaste for her own body. Jess, whose disability was acquired recently, further explains how her body confidence shifted since becoming disabled.

> Now that I've had weight issues [since the car accident and onset of my disability], the way I see my body, I don't find myself really attractive in this sense. Whenever you watch television, an attractive person would just stroll into the room and be like perfect. And I'm just stumbling, basically (Jess).

Embedded within Jess's description was the presumption that bodies without disabilities are more attractive than those with. Interestingly, Jess's quote also captures the personal impact on the societal preference for bodies that occupy and move within a space in a way that represents

health, fitness, fluidity and grace. In other words, without disability, abnormalities or other complications to one's mobility. Taken together, being Left Out of media and beauty representations perpetuates the societal idealization of fit and healthy bodies. However, it was not only the missing images that evoked an impact, the images that were represented also contributed to feelings of body dissatisfaction and other embodiment differences for women with disabilities. These themes will explored in the next subcategory.

Unobtainable Goal Of The Ideal Body

The second subcategory under Media Messages expands on the previous category to capture how women without disabilities, without adequate representation of disabled bodies in media to emulate, will begin to aspire to achieve a body that is represented in media: an able-bodied thin woman. Even if women knew that they might never reach that ideal body type, they still aspire to it, sometimes as an effort to offset their perceived limitations as a disabled woman.

> Social psychology dictates that symmetry is the most beautiful shape so I feel, fundamentally, that I will never be understood as conventionally attractive or be the beautiful that sells cars. As much as I want to be beautiful to one person, I would love to be the type of woman that causes car accidents, bar fights, and people to forget their names. I think that's really unobtainable. Oh, and I have a huge forehead and I hate it (Kendra).

In the above quote, Kendra discusses her wish for a more conventional type of beauty. Despite the fact that women with disabilities themselves are often represented by limiting stereotypes, the women in the study are envious of women without disabilities who are objectified to their appearance and body. In this instance, the goal that is expressed is that to be treated like 'regular' or nondisabled women. Sexual objectification is preferred to being perceived as disabled, invisible, and asexual. Sexual objectification is achieved when a woman is able to

distance herself from her disability and resemble a prettiness or beauty that sells magazines and beauty products.

> I heard a lot of men like the locker room talk with a lot of objectification of women's bodies. I would often get conscious about, as much as women don't like to be objectified, I would be concerned because I don't look like that. No one else is talking about me like that. It became really intense (Kendra).

Other women who were interviewed discounted themselves as ever being considered conventionally beautiful, according to media-defined standards. However, in contrast with Kendra, they interpreted this understanding as a protective factor. If a woman decides that she likely never will have the 'ideal body', then she might as well sit the race out and enjoy the view.

> I've come to a realization that the media or society, in general, will never see me as that perfect standard. So why worry about it? For the most part, I'm glad for that. I think I've come to that conclusion a little faster than some able bodied friends. Those ideals are not measurable for anybody, unless you drastically alter yourself by artificial means or something. I don't know. Part of me almost wonders if that's me coming to a realization or me counting myself out? (Mariam).

As Mariam's last quote highlights, being able to come to peace with the lack of media representation for disabled bodies took time, self-acceptance as well as a sizeable amount of reframing and coping on her part. In the next section, I will explore another social space where disabled bodies are, alternately, a topic of great interest. Within a medical context, disabled bodies are objectified and studied as abnormal or medical errors.

Abnormal Bodies

The fourth second-level subcategory under Embodiment Differences represents the experiences of women with disabilities who understood that their bodies were Abnormal in some way. This subcategory differs from the others (Body Esteem, Sexuality And Relationships, Media Messages) in that it refers to how women received messages that

disability is abnormal. Under this model, disabled women's bodies are reduced to a number of complications, a diagnosis, or an incomplete/broken body caused by a medical mistake or anomaly. Their bodies serve as an example of all that can go wrong with a person's health, functioning, and mobility. Women discussed the experiences of being objectified medically by healthcare professionals in attempts to fix, cure, and make more normal. All of the women in the study understood, from an early age, that their disability represented some sort of defect or difference from a healthy, functioning body. These definitions and messages were garnered originally from the doctors who diagnosed them with their disabilities and later maintained by other healthcare professions, educators, parents, and support people they encountered. The medical model of disability is largely seen as the primary lens which we understand disability. However, this viewpoint, and the reductionistic language used to express it, has had an impact on the body image and body-esteem of all the women in the study.

Participants described how they understand their bodies are perceived of in the medical community. The word 'Disfigured' was chosen as it left a powerful impression on many of the women in the study. Although it may be helpful, at times, to understand how a person's body differs from that of the 'norm' for treatment and diagnoses purposes, if this has been the only exposure a woman has had of her body, it can contribute to feelings of being 'less than', 'apart from', and/or 'broken'. There is an underlying assumption that women experienced where the disabled person is 'incomplete' and that they are in need of rehabilitation, fixing or curing. In this first quote, Mariam describes how a medical view of her body has impacted her.

> I mean you feel really reduced right. It's reduction of a person and you're down to a diagnosis. [You're] literally talked about in clinical terms and maybe you don't want to hear that about yourself. I actually had doctors- well, therapists- call me disfigured because of my scoliosis (Mariam).

The descriptor "disfigured" was a particularly triggering word for women with physical disabilities. It's use brought up images of monstrosity and otherworldly beings. Mariam speaks about the associated images she had when the doctors used the word disfigured to describe her. She explains that: "The first thing that popped into my mind at that point was the movie the Hunchback of Notre Dame and how it's reviled and sort of avoided."

Reducing persons to medical problems is a form of medical objectification of person's with disabilities. For women with physical disabilities who already struggle with multiple messages of undesirability, this medical treatment and the use of medical jargon can be particularly damaging. Further, women spoke about getting messages about their body being objects for medical attention and scrutiny at a very young age. There was a shared understanding that medical professionals had permission to examine and study their patients. Body autonomy for women with disabilities was challenged in these highly medicalized settings.

> Maybe because I've grown up with my disability, I expect, in that environment, my body to be scrutinized. My disability and my impairments to [also] be scrutinized. Everything to be put under a microscope. I didn't understand what they were doing at that young of an age (Jennifer).

As Jennifer highlights, not only did medical objectification contribute to negative feelings associated with her body and its desirability, but it also has a strong impact on her sense of body ownership and autonomy. From a young age, Jennifer was taught by the medical community that her body should be available for medical professionals, regardless of her feelings and/or the purposes for any examination or medical test. The theme of loss of body autonomy in medical settings will be explored further in subcategory about Medical Trauma. However, it is important to highlight in this section that the medical objectification of disabled

bodies is a significant contributor towards embodiment differences and how women with disabilities and others both understand and tolerate/love their bodies.

Women also described how being treated as asexual in a medical setting had a negative impact on their body satisfaction. Participants described how this representation has had deleterious effects on their self-esteem, body esteem, relationships, and sense of belonging and entitlement. For many women, sexuality is associated with shame; however, this is particularly true of women with disabilities who are completely denied as sexual beings. Women with disabilities are viewed as child-like and innocent.

> It would be really interesting to see a different sexuality of the woman with a disability that wasn't shrouded in shame or mourning of a loss of sexuality (Kendra).

Participants described a need to advocate for themselves as sexual beings. Further, they discussed how these out dated stereotypes negatively impacted their reproductive and sexual health. For instance, Jennifer recalled an instance where she attempted to receive birth control. She describes how: "As a woman with a disability, you go and you list your drugs and one of them for me is my birth control. And then, I often get 'Oh yes, birth control to regulate your period'. It's like 'No, birth control for birth control'". As a result of these attitudes, women shared how they themselves often had to initiate discussions about sex and sexual health, which was often followed by microaggressions or other attitudinal barriers.

> If I go to a doctor with a specific question about sex and I get the "judgy" look. You know, like, either I'm lying about having sex, or something's wrong here. Something's not quite right if a woman with a disability is asking questions about reproduction and other things. That's when it kind of gets uncomfortable for me (Jennifer).

Not only does medical objectification and being denied sexuality negatively impact the woman's body-esteem, but it also has broader implications with respect to the women's

willingness to engage with healthy supports as well as other social supports, including romantic partners and friends.

Social Differences

The last first-level category subsumed under the main category of The Experience Of Difference related to how women with disabilities experience feeling different in terms of their identities within relationships and broader sociocultural spaces. In this category, women explored how being disabled was tied to social power and position. Here, disability and difference is often equated with rejection, isolation, distancing, and feeling invisible to other people as well as community-based research, programs, and services. Disabled women experience their social value and worth as community members as limited; their very presence and existence in social spaces is deemed problematic. As described, internalizing their body as problematic has vast implications on disordered eating practices and body satisfaction. In addition, social marginalization interacts with many other social supports necessary for healthy living. The category was further broken into four second-level subcategories, including Intolerance For Difference, Lack Of Acceptance And Inclusion, Developmental Importance Of Puberty, and Hidden In Plain Sight. Each subcategory describes different ways in which disability and difference is not tolerated and, at times, actively excluded or punished and how that impacts eating behaviour and body image. Further, each of these subcategories has a number of subthemes that will be explored below.

Intolerance For Difference

The first second-level subcategory subsumed under the Social Differences category is Intolerance For Difference. This category represents the limited understanding of disability and other bodily differences that are perpetuated in society. The term body differences, in this context, was used to refer to ways in which a person's body is perceived as problematic besides differences due to disability. Mostly, I will be referring to bodies of larger size or fat bodies

when discussing body differences, however, this definition could be expanded to include other types of "problematic" bodies (e.g., racialized, transgender, etc.). In this category, both disability and body differences are viewed as socially problematic because such bodies cannot be easily accommodated by society. People who live with disabilities or body differences are stereotyped as unproductive, burdensome, and lazy. Further, their quality of life is also perceived as low and the assumption that persons with disabilities are suffering tends to cloud other assumptions about their lives. This category explores two ways (subcategories) in which persons with disabilities and body differences are viewed as negative in society, namely, Problem Of Disability and The "Fat Disabled Girl", which will be explored further below.

Problem Of Disability

The first subcategory, Problem Of Disability, captures the experience of participants who felt that their physical disability was viewed as and treated like a problem. Participants discussed how disability was almost always understood and framed as an issue, limitation, or deficit to be overcome, cured, or fixed. In other words, an attribute that differed from the norm in a negative way. When answering the question regarding how the difference associated with disability was experienced, Jess replied: "There is a not normal that's not okay and a not normal that is okay. The not normal that to me would be not okay is feeling less, deficient compared to everyone. That is how I see it." Women interviewed understood the perception that disability renders them 'less than' within their environments from a very early age. Some women spoke about how the first people to convey or introduce the problematic nature of disability were their families. Heather, who was born with a congenital amputation of her hand and lower arm, recalled her father's expression of distress over her disability.

> The only time I saw my dad crying growing up was when he was telling me "if I could do anything, I would give anything for you to have that hand and to make life easier

> because I can't imagine what you go through." For me, it was just like he was making it sound like the worst thing in the world. I was like, crap, it must be really frigging bad if my dad can't deal with it (Heather).

Mariam, who was born in Pakistan, recalled how disabled people were feared and rejected in her first cultural home. She explained that "having a disability in my culture and my family background was considered such a horrible, horrible thing. I had heard statements like disabled people didn't deserve to live." Most participants felt that their disability status and identity was unjustifiably coloured as negative due to the limiting, reductionistic and fatalistic understandings of disability. Most women spoke about being unfairly judged by other people based solely on the fact that they have a disability. Interestingly, it was not necessarily their disability or their perceived differences that bothered the women. Rather, participants spoke about the fact that the people closest to them absorbed these negative messages about disability that negatively impacted them. For instance, Heather recalled: "When I was younger, I noticed the way it [physical disability] affected my family more than [it did] me. Noticing someone staring at their daughter or their sister, I couldn't control that. I guess that's where my [eating] control issues started." While Heather's family attempted to protect her from damaging opinions and open stares in the outside world, it was her family's discomfort with her disability that made her feel particularly isolated and excluded. Heather also communicated her own struggle with trying to limit the pain and discomfort experienced not by her, but by her family, when exposed to negative messages about disability by hiding her disability in public or drawing attention to perceived physically attractive qualities. Related to this category, women repeatedly received messages that their bodies were problematic, either the way they functioned (e.g., using a wheelchair, chronic pain, etc.) or the way they navigated the world (e.g., needing accommodations). These messages have a lasting impact on women and how they understand

their own value and worth. Emily, for instance, described her own quest to become 'normal'. She explained: "I'm still not able to accept it. I'm still convinced that I'll find a surgeon. In my head, it's still going to get fixed." Further, in terms of its impact on eating, not only did women describe feeling a need to lose weight in order to fit in better, but some discussed how their efforts to hide their disability negatively impacted their eating. Emily reported that "I did have problems at university with eating in public. During my whole time I had lots of anxiety. I did not eat in public. Probably because people would see my hands." For Emily, her anxiety around people noticing her disability prevented her from eating around others. In the next section, I review how dieting was a common tool used to avoid experiencing a powerful form of weight stigma that was unique to disabled women.

The "Fat Disabled Girl"

In addition to negative messages about physical disability, women interviewed also spoke about experiencing negative messages regarding their body size, weight, appearance, and shape. In these cases, body differences of being overweight, fat or obese were, for some women, more difficult to accept. Women with disabilities also felt that their bodies were judged more harshly than women without disabilities for being overweight. In other words, the perceived problematic impact of excess weight was exacerbated for women with disabilities. In the quote below, Carrie discussed how people with disabilities and fat people share similar stereotypes around poor self-hygiene.

> I hear that skinny people are more likely to get hired than overweight people. I feel like, "Gosh! I'm fat [and] disabled. I'm never going to get a job." And a fat disabled woman that doesn't take care of herself – physically, appearance-wise - is really…you don't want to go there (Carrie).

Carrie further suggested that as a disabled woman, she already could barely manage the negative perceptions of living with a physical disability. She is unsure if she could handle the

additional judgment of also being fat. Moreover, women discussed in general how being labelled as both fat and disabled, regardless of the person's actual abilities and/or fitness level, is perceived as unhealthy, lazy, and as overall burdensome. As described below by Carrie, the assumptions that accompany health and functionality of disability and obesity become exacerbated when combined.

> I think it's worse to be disabled and fat because society doesn't look at disability or obesity as good qualities. There may be assumptions with disability that you're not really contributing to society. You're kind of useless. Pity party. And then for fat people, people might think they are lazy. People might think they are unattractive. People might think they are unhealthy. They can't have kids. Which also goes with the disability thing. So, I feel that it's worse to be overweight and disabled (Carrie).

The negative views of fat disabled people were not only contained within fears about societal reactions. Participants themselves had negative and oftentimes harsh views about disabled people who were fat or overweight. In the following quote, Kelly describes her frustration with fat disabled people who she assumes caused their disability by gaining weight. In this situation, it is not simply a distaste for fat bodies, but rather a more judgmental attitude based on the assumption that the individual in question chose to 'let go of themselves' and, as a result, gained weight that led to their becoming disabled.

> No wonder they're using a wheelchair. They're so fat they can't support their own weight! That's extremely unfair. Why do they get perfectly healthy bodies to ruin with junk food and I get stuck with this body? I'm trying to look after my body and be healthy. Then, they get to use a wheelchair because they're too lazy. I found that really unfair (Kelly).

On the other hand, for Hannah, she explained that because her disability is nonvisible, she experienced greater difficulty with others judging her based on her size.

> I eat very healthy but physically, it doesn't show. I feel like people judge me because of the way I look. That also impacts me eating publically. I notice that I'd rather eat at home, or in the library, where no one is going to see me because I just feel judged. Even though what I am eating is good, I just feel like people will look at me judging, you know? (Hannah).

When people are aware of her disability, such as when she goes to the doctor, Hannah further discussed how she felt more harshly judged because there is an assumption that she is intentionally creating chronic pain problems for herself by not losing weight. Hannah explained: "You're always judged. Any specialist I see, they'll always say 'Well, you need to lose weight.' If I say, 'But I eat well, and I try to be as physical as possible,' they just look at you like 'That's not true.'" For others, particularly those with acquired disabilities, this negative view of disability created fear and worry about their futures, particularly in the area of potential romantic partners, health and career success. Similarly, Carrie explained how: "My father gives me a speech about losing weight. It's always about how are you going to move when you're 40". The societal bias for fit, healthy and 'normal' bodies negatively impacts women with physical disabilities who will likely never possess the preferred attributes. As fat or obese bodies also stand directly opposing these preferences, women with physical disabilities experienced a strong desire to lose or maintain their weight.

Lack Of Acceptance And Inclusion

The second subcategory (second-level) under Social Differences refers to the experience of women with physical disabilities of feeling and being not fully integrated and accepted in social groups or programs. Related to the overall core category of The Experience Of Difference, women specifically felt excluded due to their physical disability and body differences. In some instances, women were outright rejected, ignored or excluded due to an attitudinal lack of acceptance for persons with disabilities. These instances were common during high school and post-secondary education. More often, however, women discussed being more subtly excluded due to a lack of effort related to physical accessibility issues. Regardless of the method of exclusion, the results appeared to have a significant psychosocial

impact on the women. Further, the impact of this exclusion seemed to colour future social interaction in that some women had come to expect being treated as different or being excluded. Subsumed under this category were two subcategories that each explored different ways that women understood that they were not accepted or fully included in social settings and other recreational programs and how that, in turn, impacted eating and body image. This included the subcategories: Isolated And Invisible and The Unexpected Guest. Each will be explored in detail below.

Isolated And Invisible

The first third-level subcategory under Lack Of Acceptance And Inclusion highlights how women with physical disabilities often felt very much alone, isolated, and ignored completely from other people, especially groups of people. Women spoke about having particular difficulty fitting in with groups of peers during high school and college. Even when women did have peer groups that they spent time around, there was still a feeling of not being completely accepted and integrated, meaning they often still felt different from their peers without disabilities. Kelly discusses below her experiences in high school where she felt isolated and not included with her peer group.

> I wouldn't really call them friends, I would say they were like school acquaintances. We never hung out after school. We were friendly to each other and they did let me hang out in their group at lunchtime. But, they didn't really interact with me too much (Kelly).

Kelly eventually breaks away from being around school acquaintances that she believes were not really interested in being her friend. Despite a number of women interviewed having similar experiences to Kelly, each had individually believed that at least part of their social exclusion was their fault and/or resulted from some lack of personal effort. Later, when Kelly moves to a

new high school, she continues to experience difficulties fitting in with her peers. However, this time around, she feels completely alone to the point of being invisible.

> I was never bullied or anything, I was ignored to the point where people would literally pretend that I wasn't there. One time, the teacher got other students to hand out the papers to everybody and I remember that I didn't get mine. They had deliberately missed me. I was just completely ignored and you know was treated like I didn't exist (Kelly).

Even amongst participants who had a number of able-bodied friends, there still remained a feeling of difference and being set apart from the group. Sometimes this difference would be conveyed in the context of being left out due to physical accessibility issues. Other times, it was more a feeling of difference and inferiority. This would be expressed often in attempts to alter clothing, appearance, or weight to fit in better or demonstrate popularity.

> My girlfriends in high school, were not some sort of prissy, super-popular girls, or whatever. They were very much like, you know, Clare Danes in *My So Called Life*. You know, your average sort of preppy, cute type of girl. But I still felt like I was just shy of that. I could have done better to fit in even more with them. It was frustrating, not to be able to get to the same weight (Jennifer).

In addition to feeling set apart from peer groups, some women interviewed felt further isolated from larger social or cultural groups with which they identify. Jess, who also identifies as a woman of colour, reported constantly feeling different or apart from the community of black women. She explained below that she feels like an isolated minority person within two already marginalized groups.

> I feel like the first thing you're defined as is a person with a disability and then afterwards it's Black or it's Asian. But the first is the person with the cane or the person with the chair that is defined. As a woman, even though they have experienced discrimination or have been put as somewhat less than men, they are big group of woman, so I would say they are stronger. But with a disability, that sets you apart a little bit from this big group of women. It puts you in another category and because there is less [women with disabilities] that puts you in a fish bowl (Jess).

Jess argued that her disability status and also her disability-related appearance further separates her from any potential community groups due to a limited presence of disability within these

groups. Similarly, Mariam describes how her disability is judged harshly in her culture (Southeast Asian) and how she uses weight control as a method to navigate that social exclusion.

> Disability in my culture and my background was considered such a horrible, horrible thing. I had heard statements like people with disabilities didn't deserve to live. That's the kind of messages I had heard at the beginning of my diagnosis. Obviously, where does my body image go? [Where does] my mental health go? It's tough (Mariam).

Women further felt that they were rejected or marginalized from common social locations and positions. In most cases discussed, the women felt that their disabilities and differences were understood as inferior and undesirable. Below, one participant discusses her main issues with her disability that negatively impacts her life and her ability to interpersonally connect with other people.

> Just being liked. I guess if you can just be liked, then maybe it won't matter. It won't become a big issue. Living with a disability, you can't really hide. When somebody sees you that's the first thing [they see]. You don't want to be judged just as that girl with a disability, that girl with the wheelchair (Jess).

As with many other categories, the experience of social rejection or being invisible contributed to mental health problems and disordered eating. Women discussed how focusing on eating and weight loss goals helped them to cope with other challenging aspects of their life. In many examples, participants described how becoming wrapped up in their eating disorder distracted them from aspects of living with a physical disability in an often inaccessible and unwelcoming society. In the example below, Kelly spoke about how she was not bothered by the fact that students at her high school completely ignored her as she was so wrapped up in her eating disorder.

> I think because I had already started to go through all the effects of an eating disorder by the time I had changed to that school, I wasn't able to make friends simply because I didn't want friends. I wanted to be wrapped up in my own disorder. I didn't want to get close to people in case they noticed that I didn't eat (Kelly).

Feelings of isolation and social rejection were two of the more upsetting experiences that some women with disabilities described. For Kelly, her eating disorder provided a comfort and a distraction from these feelings to the point of where she recalled preferring not to have any friends.

> I guess in a selfish kind of way, I didn't care. I had a lot going on in my own head. My thoughts would always go back to calories that I had eaten and calories I was planning to eat and meals that I was planning for months in advance. Staying in control of what I was eating, making sure that I didn't eat anything. It was quite exhausting now that I think about it (Kelly).

Further, there may be an adaptive or practical connection between the use of food for mood enhancement related to self-confidence and physical disability.

> I think food can be an extension of self-acceptance. It can be one of the most used ways that people with disabilities can [self-medicate]. Most of us live in poverty. It can be expensive to be an alcoholic. Food just seems like an easy addiction. People who are not in a good spot with their bodies and might be depressed and, instead of having a drink, they may have something that is more accessible to them (Amy).

In many different ways, the value and worth of persons with disabilities are questioned in society, which has a negative impact on one's mood and self-esteem. Further, similarly to those without disability, women cope with these messages in different ways and a common and easily accessible activity that can ease negative emotions is overeating or overly controlled eating.

In addition, feelings of social isolation contributed to women searching for other ways to be accepted, which often interacted with disordered eating as a method to achieve that connection. For many of the women interviewed, they sought intimacy and attention from men as a form of body acceptance. Connecting to another person in a way that was not defined by their disability or their caregiving needs allowed them to feel their own defined sense of normality and human embodiment. Finding that connection made them feel okay with being different and disabled.

> It's the first time that I felt that someone can see me as a whole woman, a complete woman. He didn't care about what I was missing. That was definitely empowering. It was very helpful. He was actually the one who motivated me to start the blog and be more open about it. I almost felt like now that he accepted me, it was okay to come out of my shell more. Because, if I did get rejected the way my grandparents rejected me, it wouldn't feel as bad because I knew someone had chosen me (Heather).

Outside of intimate connections, women also discussed how food was intricately tied to connecting with other people. Food and eating was a social activity that participants could enjoy with their nondisabled and disabled friends. In many ways, eating out with friends at a restaurant circumvented many of the accessibility barriers that persons with disabilities experience.

> As someone with a disability, I find that the experience or activity of going out to eat is one that I can fully participate in. The other thing is that a lot of my friends don't have accessible houses. It's a great alternative to meet at a restaurant. There, we can be all be grown ups and I can drink and pee freely. I think that was a huge thing in moving to Toronto. I wanted to meet new people. It became really important to go out and eat (Kendra).

In addition to the practical accessibility of eating out, the women spoke about how eating out helped them to feel connected to other people emotionally.

Many of the women eventually sought out acceptance amongst other persons with disabilities. For many of the women, there was a deeper connection with a person with a similar disability experience which helped them feel greater self-acceptance. Further, the process of connecting with another disabled person can also lessen feelings of isolation and the shame associated with being different and disabled.

> I think that it maybe would have been nice to have other peer support and some counselling at that point. For one thing, it would have been nice to hear someone who, for lack of better words, has ‘been there, done that.’ I think that's an effective way because it's a concrete example of seeing that there's hope. The other part is that any formalized counselling could help you work through whatever you're experiencing and dealing with. I think that would have been really great (Mariam).

Connecting to other people is an essential life goal for women with a disability, especially given that they are often left feeling excluded or ignored within mainstream society.

The Unexpected Guest

The third subcategory in the Lack Of Acceptance And Inclusion category discusses how social spaces and locations can inadvertently discourage the inclusion and acceptance of persons with disabilities by not offering full accessibility and/or accommodations. This then has a residual impact in which the establishment believes persons with disabilities are not interested in the facility/program or that they do not require the service because they do not attend, which inadvertently reinforces isolation and social stereotypes about what disabled persons do or do not enjoy and participate in (e.g., disabled women do not go to bars). The metaphor of an Unexpected Guest captures the experience of women with disabilities who often felt like they were not expected to occupy some space and, as a result, may not be appropriately accommodated or included. This metaphor was also used to quite literally embody the awkward interaction that inevitably ensues when a disabled person attempts to access a service or space in which they were not expected. The psychosocial impact of always feeling unexpected and like a burden was a theme that was common in the interviews.

Mariam discusses what it was like for her to have a physical disability within a cultural context that understands disability as a terrible affliction. In a way, Mariam's disability and her intention to live a full and happy life with a disability was not expected in her culture. At that time, it was challenging for her to even imagine this life as a possibility, particularly in a country where she had never been exposed to other people with disabilities.

> I had no idea that power chairs existed. I had maybe seen a picture of a wheelchair once. In South Asian culture, it is very hidden. Disability is absolutely hidden and completely something to avoid. In fact, there's actually no accessibility [where I am from] (Mariam).

Within South Asian culture where disability and accessibility are completely absent, Mariam's presence and very existence as a woman with a physical disability was unexpected. Her family made the decision to move in order for Mariam to have a fulfilling life without the burden of being completely rejected and isolated from society.

Women interviewed also spoke about how their presence was particularly unexpected in fitness programs and disordered eating programs. The participants discussed how there were a very limited number of exercise programs that were specifically developed with disabled people in mind. These programs were necessary for some women who required adapted equipment or extra support from staff to participate fully. For Carrie, she discussed her frustration with being only able to participate in one program in her community.

> There are not many places that you can exercise so I feel stuck. You got a gym around your home but they don't have the same equipment that you need. I can't join a different gym. I don't have the money for a regular gym but there is no point even if someone bought me a membership (Carrie).

Carrie further highlighted how financial barriers can negatively impact a women's access to health, mobility, and fitness programs. For other women interviewed who are able and have attempted to participate in a fitness program not specifically designed for people with disabilities, they shared some of their difficulties integrating into these program. Kendra discussed what it was like for her to be the only disabled woman in an Aquafit class.

> People are far more comfortable intervening into my workout to tell me what they think, whether that's positive or negative. It's actually one of the reasons why I don't take Aquafit anymore. There was a scandal when I wheeled into the pool. These older women were all staring, pointing and whispering and conferring with each other. I've had a number of the women tell me I'm beautiful but they're sad because I'll never get married. That's not something I want. I want working out to make me feel strong and powerful. Not sad and annoyed (Kendra).

Kendra's differences from the other women are immediately noticed within the space that she was not expected to attend. Although she was physically able to participate in the program, she feels socially isolated. Further, her body and presence become a display for the other women who immediately ask her intrusive personal questions. The patronizing comments and questions further alienate Kendra and contribute to her disempowerment and psychological frustration. In the end, Kendra decides to not attend the class any longer. This may also present as a service specifically designed for disabled persons in which the individual feels stereotyped and overmedicalized. Here, assumptions about physical activity may be made based on the fact that many disabled people work out at a rehabilitation facility, only because it happens to be one of a limited number of accessible fitness facilities. For instance, Kendra explains how "I think that socially my endeavours into fitness are taken up as I'm either here for like some sort of rehab and my ultimate goal is to learn how to walk or I'm going to the Special Olympics." On a related note, Kendra further describes her experiences being physically active with a disability and participating in adapted sports.

> It feels more patronizing. It feels more like rehabilitation. At this stage in my life, I resent being part of something that someone could get volunteer hours or an award for doing. If you're going to coach me, you're going to coach me because you have a passion for this sport, not because you feel sorry for me (Kendra).

For Kendra, the lack of presence of disability in these social settings contributes to her difficulties attending physical fitness programs.

> If a 29-year-old able-bodied woman living in the west end, it makes sense that you would buy a Bali's, Extreme Fitness, or Goodlife membership; whereas, for people with disabilities, there's always an assumption that it'd be a really good idea if I went to the hospital or a rehab centre to work out. There has to be some psycho-social-emotional impact if you're constantly being pushed into spaces of rehabilitation or spaces of segregation. If you're attending fitness in a hospital or a retirement home, you are not going to make active friends who want to invite you to go to the spin-a-thon or a swim. You're going to meet people who want to meet you for cake or for a sedentary activity (Kendra).

The lack of access and inclusion in mainstream gyms and other places of physical activity had a significant impact on the health and social well-being of women with disabilities. Also, participating in segregated sports or exercise programs housed in rehabilitation or hospital settings further reinforced the idea that disabled bodies were different, separate and apart from nondisabled exercises and, as a result, required medicalized support to engage in physical activity.

Alternately, when women were able to find supports, they described how helpful and fulfilling it could be. However, accessibility for them did not just imply being able to enter a building with their wheelchair. Rather, being included meant providers and supporters had a deeper understanding of disability and what it means to include difference.

> I ended up Googling psychotherapy for women with disabilities and Attention Deficit Disorder (ADD). I found a woman in the east end of Toronto who does psychotherapy and who happens to self-identify as having ADD. She's been really good about tapping into various experiences of self-worth and self-hatred. I think it helps that she also identifies as a disabled woman because she's able to pick up on those things. My sense prior to her, in terms of some of my experiences with finding other interventions and support, was that sometimes my experience with disability is used as a master status to explain 'why I everything' (Kendra).

Similarly to Kendra, Emily was successful in finding a therapist who, although not trained in disability issues, was open to learning and receptive to feedback.

> She was a resident when I started seeing her. She didn't know anything about disability and was very open about that. She did research and different things so she learned with me. She was aware that my disability was definitely central to a lot of things (Emily).

Of note, each woman tended to have different hopes and expectations for their therapists. Although most in the study identified wanting a therapist who was disability-aware, at least one participant highlighted that she wanted to be treated like a person without a

disability. “If someone were to eavesdrop on the therapy, they wouldn’t know that I have a disability” (Michelle). In the next section, women discussed how puberty was a particularly vulnerable time for highlighting their social differences.

Developmental Importance Of Puberty

The third second-level subcategory under Social Differences explores the social changes related to puberty. For most women, puberty is a time period that represents numerous biological, psychological, and social changes. It is generally the time when girls start expressing interest in romantic partners and sex. It also represents a chaotic social time when cliques and groups are formed. For many, it also signifies a transition from primary to secondary school. For women with disabilities, this time period was at least as important and impactful; however, this was also the time period that represented the moments when disabled women (those with congenital disabilities) became increasingly aware of their disability and how it contributed to social and embodiment differences from their peers. Unfortunately, for many of the women, this time often was accompanied by mental health issues. Mariam described how beginning to use a wheelchair and experiencing puberty was a particularly difficult combination.

> I was in chair and I had to express my negative feelings somewhere. Honestly, I was going to have a nervous breakdown. I would diagnosis myself with depression. It was horrible. Everything looked grey and hopeless. I didn't want to burden my family with it (Mariam).

Further, this was also the moment that, for the majority of participants, they recalled feeling dissatisfied with their appearance and began engaging in disordered eating in an attempt to curb that dissatisfaction. For example, Heather explains: “Definitely, when I was in eighth grade, that's when I said, ‘How do I get the boys to like me? How do I become pretty. I’ve got to lose weight.’ I have, to a certain extent, control over that and it was something that I really strived to control.” Similarly to many women without disabilities, participants spoke about the physical

changes associated with puberty were a trigger for body dissatisfaction and subsequent dieting. For some, puberty signalled the fearful emergence of excess body weight and fat.

> When I was around nine and I started puberty, I felt I was getting bigger. I got really concerned about that. My mom was like, "If that's how you feel, I'm going to take you to the doctor. He'll set you straight and fix the way you see yourself." So she knew (Michelle).

> I guess probably around the time that I actually hit puberty. That's when I'd put all the weight on. I used to always be really skinny. I'd always have bones sticking out. Once I hit puberty, my weight just piled on (Kelly).

For others, there was a reinforcing quality to losing weight during that time, as it was typically the first time for the majority of the participants that they became aware of their body and other people's reactions to it.

> I know that for a lot of girls when they go through the changes and become a woman, they gain weight. They put weight on their hips. But for me, since I was already chubby, I lost the baby fat. I was average weight by then so it wasn't like I was very heavy. Then, I just got really thin. I thought I was great. I felt empowered (Heather).

For other women with disabilities, their body dissatisfaction at puberty was greatly tied with negative messages and feelings about their physical disability. For many women in the study, puberty was also the time that they had some severe physical changes associated with their disability. This was a time when body dissatisfaction related to disability was particularly heightened. For Carrie, she had undergone spinal surgery. She described in the quote below how this major life event impacted how she felt about her body and ignited her motivation to lose weight.

> I had surgery and grew hair all over my body because of all the drugs I was on. It was just one thing after another after another. Then, I felt so great after surgery because I was so skinny. [I didn't need to lose weight]. It was more about me thinking I was only chunky because I was crooked. I thought that I had to straighten out my spine and my tummy would go away. It became this thing. I have pictures of myself in PJs and a belly top right after surgery (Carrie).

Some women spoke reflectively on how there were particularly stressful times in their lives where they would have greatly benefitted from psychotherapy; however, they were not offered or made aware of those resources.

> When I transitioned to [using a wheelchair], I wished there had been more mental health resources at that time. I was offered absolutely nothing. That was by far the worst period I experienced from a mental health and general health perspective. I was given no psychological or emotional support at that time (Mariam).

Similarly to Mariam, other women interviewed explained that therapy would have been particularly helpful for them during adolescence. This category will explore three subcategories that each capture the relationships women spoke about between puberty, body dissatisfaction and disordered eating, and attitudes and feelings towards their physical disabilities.

Highlighting Differences From Peers

The first subcategory (third-level) under Developmental Importance Of Puberty attempts to capture one of the primary reasons that puberty was so difficult, particularly for women with physical disabilities. Many women spoke about how they were less impacted or less "disabled" by their physical disability prior to high school. However, once high school began, women felt that there was a social shift in which hanging out with friends during recess was replaced by cliques, gossiping, parties, and dating. Suddenly, women felt that their appearance was important. In the caption below, Jennifer discusses how her need to diet first emerged alongside pressures to be popular and desirable to boys.

> Sometime around middle-school, or preadolescence, was when I first started self-restricting, although not always very successfully. But certainly peer acceptance, wanting to have a boyfriend and be desirable to other people, and wanting to look and feel like you were pretty and popular definitely played a role (Jennifer).

In the next quote, Heather discussed below how she felt both the same and different from other young girls.

> I think as a female, it's something that a lot of girls go through because I know a lot of my friends - not disabled - have some of the same worries. I've had a long day and I look like a mess. Where can I get a nail polish that won't chip or a hair gel that will stay in place all day? I think that's not directly related to my disability. But, my disability did intensify it and made it more of a worry, than a healthy concern (Heather).

Heather's distinction at the end of the quote between being slightly concerned or obsessively worried about her appearance highlights one of the main differences participants explained between women with and without disabilities. In other words, women with disabilities reported feeling like they had to participate in the same race to be popular and beautiful alongside women without disabilities, however, disabled women were starting the race already in last place because of the negative social impact of their disability. If a girl without a disability spends 15 minutes fixing her appearance each day, then a woman with a disability would require an hour because they had to 'make up' for the negative scores cause by their disability.

In addition to concerns about appearance, women with disabilities also discussed how puberty was the first time that they felt socially different from their peers. In the next quote, Jennifer discussed her experience as a rebellious teenage with a disability and how she felt it differed from teens without disabilities.

> As you get older and you're in high school, people are going out partying and drinking or doing stuff that requires deceiving the parents. It became more difficult to interact with my peers on the same level. You end up a little bit detached from the rest of your peers. At a certain point, that did become difficult for me to cope with emotionally (Jennifer).

Interestingly, some women interviewed appropriated characteristics of what they viewed to be a part of same-aged women without disabilities. In other words, the women took on beliefs and behaviours they witnessed in their peers as a way to fit in and connect with other women, even though these beliefs and behaviours were unhealthy and, sometimes, dangerous. In the first

quote, Kendra recalled how her body dissatisfaction and disordered eating behaviours were almost a prerequisite to be a young woman in high school.

> I remember it was almost invoked in my high school to hate your body. I don't know anyone who didn't have a weird relationship with eating. At that point in my mind, I think some of it was that I was hoping to garner attention. It was perhaps a mechanism to break out of that experience of being the disabled girl because then I could be the weight-conscious girl (Kendra).

These problematic eating behaviours also transformed Kendra to a more socially appropriate stereotype. Taken together, puberty and the emergence of adolescence did not only bring about increased pressure to attend to appearance, but it also highlighted peer and social differences between women with and without disabilities. For many women in the study, it was the first time they felt set apart from their peers in a meaningful and impactful way.

Bullying And Teasing

For many women in the study, puberty and high school were particularly difficult because they were teased and/or bullied by their peers. Many of the women interviewed recalled very painful and hurtful moments where they were insulted or degraded in front of peers. Many of these instances shaped these women's future body esteem, romantic life, and reinforced unhealthy weight management practices. Further, the teasing and bullying were frequently related to physical and social differences that stemmed from their disability. In the first example, Jess describes how frustrated she became at simultaneously trying to cope with her newly acquired disability, heal from the psychological and physical trauma of the motor vehicle accident, and manage the resulting bullying and teasing from her peers. She explains that "I did have a period of time where I was bullied afterwards. I remember the girls imitating how I would walk. I was like, if not for being disabled, they wouldn't have anything to judge me on, I think." For Jess, her accident and the resulting disability was a source of constant

stress because she felt it made her vulnerable to bullying and teasing. Similarly, Kelly recalls a particularly painful event in which she is mocked in public by two men while at the Aquarium as a teenager.

> Me and my boyfriend went to the Sydney aquarium and we were just looking at the fishes. Behind me I could hear somebody making retarded noises. I was trying to figure out if they were making fun of me. My boyfriend has been to Japan and can speak the language. After we left, he said that he overhead them call me a *kathwa*, which in Japanese is crippled. That made me really upset and angry. He knew what they were saying and didn't stick up for me (Kelly).

In the examples above, peers would target an aspect of the woman's physical appearance unrelated to her disability; however, the insult would later be interpreted by the woman as proof that she is undesirable- a message that she has taken in repeatedly as a woman with a disability. For example, Carrie recalled how she was rejected by a boy because of her frizzy hair, which motivated her to never give a boy a reason to reject her outside of her physical disability.

> I was so surprised. I thought it was his friends being like, "Dude, you can't date this girl in a wheelchair." Then, to hear that it was actually because of my hair? From the middle of high school until now, I was so obsessed with my hair. It's never stopped. I went through puberty and I was this frizz girl (Carrie).

Other women in the study provided other examples of being teased or bullied for their appearance. However, for most of the women, there was more of a subtle exclusion from social groups. Most of the women were able to connect their issues with eating directly with experiences of social exclusion/criticism. For instance, Kendra recalled quitting wheelchair basketball after her coach negatively commented on her weight. She described:

> That was the straw that completely removed me from basketball. After that, I started actively trying to lose weight. I'd make myself throw up a lot. I drank a lot in first-year university. I also switched to vegetarianism, which probably wasn't the greatest weight loss strategy, in retrospect. I started eating really weird things (Kendra).

In the next subcategory, I explore how women felt living with a physical disability often meant that the lacked social capital and experienced frequent social rejection.

Lacking Social Capital

The third subcategory (third-level) under Developmental Importance Of Puberty refers to the experience of women with disabilities who felt socially different, isolated, and sometimes rejected once they hit puberty. Women spoke about how puberty brought with it a sudden awareness of social inclusion and social capital. The term social capital was chosen to represent the limited attributes that provide social capital, popularity, and acceptance for a young teenager.

> I think puberty is that time when you start to think about yourself in terms of how other people see you. Before that, it's like all girls and boys are friends. They play games and have fun. Then, after some point when you're just like, "I need to wear lip-gloss. I need to date older boys. I want to kiss those boys." It changes. The dynamic really changes around that age (Heather).

Mariam discussed below the impact of becoming more aware of her body image and the social capital in her surroundings had on her as a young teenager who was already set apart from her peers because she uses a wheelchair.

> Around the age 13 or 14, my whole body image thing kicked in to full gear because not only were you starting to get those messages but now I've had this one extra thing of being in a chair. Then, when you start getting into the teenage years, you're trying to discover your body but then you add in being in a wheelchair and wanting to still have the right attributes. In our culture, and most cultures, the wheelchair isn't exactly considered the right attribute (Mariam).

Other women echoed Mariam's difficulties and shared how challenging it was for them to fit in with their able-bodied peers. Kelly recalled how transitioning to a new school as one of the only disabled students was challenging, particularly since she was teased at her former school. She described her isolation and how her difficulties connecting with others resulted in negative psychological spiral.

> I was only at that [particular] school for a year because I couldn't handle it any longer. I changed to another high school and the friendship groups had already formed and had become quite close. I found it hard to actually make a connection with anybody. I ended

> up sinking into myself. In the end, I was getting more and more mentally sick. I didn't want to hang out with those people. I didn't want to eat in front of them. I would go to library and read. Or I'd go to the counsellor and talk to her but she didn't really help all that much. It was basically around school that I think it [her eating disorder] had all started (Kelly).

For many of the women interviewed, adolescence was a particularly difficult time. All women with congenital disabilities recalled issues with fitting in with their peers. Further, for those women like Kelly and Heather, who experienced traumatic and extremely stressful events during this time, there was a longstanding impact on their body-esteem, self-esteem, future relationships, and disordered eating behaviours. It was during puberty that most women became aware of their bodies and how they differed from their able-bodied peers. For some, this time initiated years of body hate and subsequent disordered eating in attempts to improve their physical appearance.

Hidden In Plain Sight

The final subcategory (second-level) subsumed under the Social Differences category reports on the experiences of abuse and trauma within women with physical disabilities. Through a complex interaction of factors, women with physical disabilities were at increased risk for abuse, particularly at the hands of caregivers and other support personnel. This category begins to uncover these experiences as highlighted by participants in the study. In addition, some participants who acquired their disabilities later in life had the added vulnerability of being a trauma survivor as well as adapting to their physical impairments and identity as a person with a disability.

Normalized Abuse

Related to how women with disabilities must rely on numerous forces outside of their control to fulfill basic personal tasks, such as using the bathroom, this category focuses on the

personal reactions and the responses to this dependency and lack of control. Of particular concern was the level of hurtful and toxic comments made by paid personal support workers (i.e., attendants) to the women about their body and/or their eating habits. The term Normalized Abuse was used to capture the experience of women with disabilities being in a toxic relationship with caregivers. Women spoke of accepting psychologically damaging comments from caregivers and attendants due to their reliance on these people and the very real fear of reprisal. One participant spoke about how these oftentimes toxic relationship impacts her personal safety.

> They're so part of you're personal life. You just feel judged all the time. Some people can go home and they don't have to worry about that. You just feel like there's no out for you. You're now worried that you're always expected to be a certain way when you're trying to do some things at home. That's supposed to be your safe place, right? A place where you can really be yourself. Then, you have other people in that space, saying certain things to you that make you think of yourself differently (Mariam).

Related to the core category, The Compromise, described earlier, women with disabilities in this situation were constantly weighing the pros-and-cons of asserting themselves or filing a complaint with the management regarding attendants when they made inappropriate comments. Below, this next quote details the response to whether or not the participant reports an attendant who makes these comments.

> No, because a lot of them are the ones I like. The ones I get along with. The ones who do my favours. They just feel so comfortable saying things that they think I wont take seriously. Or they think that I'll laugh about it. They are the ones who are cleaning your cat litter or making you the best food or doing your hair the way you want. It is almost like an abusive relationship. I feel like sometimes it is. Because its like: "well if I just take this horrible comment that you say with me and act like it didn't bother me, then you will clean my dishes a little nicer" (Carrie).

Over time, many women described themselves as being defeated and giving in to the constant loss of control experienced when relying on others. When women were being interviewed, they expressed a longstanding feeling of helplessness and/or powerlessness, yet it was

communicated in an almost sarcastic and very matter-of-fact manner, devoid of emotion or any other reaction. This was found across all participants in reaction to receiving inadequate support hours or other inequitable treatment that was viewed as commonplace. In the next quote, two of the participants relay what it is like for them to be constantly critiqued by her attendants, particularly with regards to weight, appearance, and/or food issues.

> "You're making too much pasta. Who is going to eat all this?" When it is clearly me. Sometimes I think that it doesn't bother me at all because most of them are pretty fat themselves. I'm waiting for the day when someone says, "you're wondering why you don't have a boyfriend." Then, I'll probably get really upset. Or, "You're not healthy. You can't take care of yourself." That would really upset me. They don't say that I'm really pretty, just chunky…It's hard because you don't even want the kind of help that they give because you wish that you could just be on your own during those times (Carrie).

> I've had that experience a lot but I don't care. I really don't. Every time they make a comment about my weight, I'm just like, "you're just jealous." That's my answer for everything. It took me a long time to get there. It's hard to do because they say really hurtful things and it's not that I actually think they're jealous. It's comments like if you get any bigger than you won't be able to move around as much or it'll be more difficult to do your care or you have a big butt or your belly's getting bigger, things like that (Amy).

Both examples quoted above highlight how hurtful comments made by persons who assist the women in their most vulnerable and exposed state can be. The quotes also suggest that this type of communication is quite common for women with disabilities. After many years of hearing these comments, both participants express some emotional distance and immunity to these verbal attacks. However, for other women, they discussed being particularly sensitive to these comments. The following participant, who is recovering from anorexia, discusses how attendant comments on weight, appearance, and food can be a hindrance to her eating disorder recovery.

> If I have a treat, they [attendants] say, "Oh! You don't usually do that?" They probably mean it in a good way, but I take it as a negative thing because I feel that I shouldn't be doing that anyway. I already feel bad enough about doing that so for someone to comment, it's hard…Sometimes, I've gotten upset after they've left and I've actually

> thrown it out. Or I've gotten so frustrated that I threw it on the floor, which I wouldn't normally do. I just have such a strong reaction to food (Michelle).

Even in a situation where the attendant care staff was not being overtly critical and interpersonally abusive, their close proximity to intimate care and support for persons with disabilities could still have a negative impact. As the examples above indicate, even small comments about weight/shape or food can trigger feelings of guilt, shame, anxiety, disgust, or embarrassment within the person with a disability.

In contrast, not all of the women interviewed believed that attendant comments of food and/or weight were a negative experience. Two women spoke about how motivating and helpful they found these comments. Due to the difficulty with weighing themselves, they often used attendants and other caregivers as a scale to monitor their size and shape.

> They'll say, "Oh, your stomach's getting so flat now." Or like "Look at that! When I first started coming here your hips hung over your pants and now they barely do at all." It's positive things like that… I actually don't quite believe them because I just can't see it (Kelly).

> My attendants don't comment on my weight, unless I've lost weight, then they comment. But my mom might say: "You've put on a few pounds, you need to start being careful." That's how I gauge [my weight]. It's very unscientific (Jennifer).

These comments also highlight how commonplace criticisms about weight and shape can become. Both of these participants above expressed highly negative comments about being overweight and fat. For them, staff or other caregivers noticing and commenting on weight was considered helpful. However, it would appear to be relatively unsupportive of accepting one's body fully, and perpetuates a particular self-consciousness around weight and shape among women with disabilities.

Medical Trauma

Medical Trauma is the third subcategory (third-level) subsumed under the Hidden In Plain Sight category. It refers to the repeated negative experiences of women with disabilities within the medical system. I chose the descriptor word trauma because the women described their experiences as highly invasive, upsetting, and dehumanizing. Further, the experiences had a lasting impact, psychologically, socially and physically, on the women. They spoke about their experiences in a highly emotional manner. Emily, below, spoke about what it was like for her to be exposed to numerous medical testing and procedures as a young woman. Similar to survivors of other types of trauma and abuse, Emily discussed how she connected her early experiences in medical treatment with her sexual impulsivity later in her life.

> I have so many memories. I had so many surgeries when I was thirteen and fourteen. Being a teenager, naked, in front of twenty surgeons, that was definitely not the best. And just being filmed, being walked in front of students and things like that. I even objectified myself with men. I met a lot of men through the Internet for one-night stands and things like that. Even my body became a sexual object to fill that void (Emily).

For Jess, who has had a long medical journey towards recovery since she was first hospitalized following a serious motor vehicle accident, described how exhausting and frustrating it is for her to deal with medical professionals who appear almost too busy to provide quality care.

> I have been through so many doctors since the time when I was first hospitalized. I see the kind of treatment I'm getting. I have even been to one doctor who had sent me for an X-ray. Then, I went back for a follow-up appointment and he had misplaced the X-ray. I was like, "Okay? I'm here to actually see how my situation is and you just nonchalantly can't find the X-ray?" (Jess).

In addition to Emily and Jess, other women interviewed spoke of similar experiences of feeling physically objectified and traumatized both by the attitudes of medical professionals and the inaccessibility of the treatment received. Further, participants expressed both fear and hopelessness at the idea of seeking any future support, suggesting that their prior experiences

had left an emotional and physical vulnerability in the context of medical treatment. This category was further split into two subcategories: Circus Sideshow and Inaccessible Treatment, which will be explored further below.

Circus Sideshow

The Circus Sideshow subcategory (fourth-level) represents the experiences of women with physical disabilities of being dehumanized and on display within the context of medicalized treatment. For many of the women who were born with their physical disabilities, there was an early understanding that their bodies were open season for medical professionals. Similar to Emily in the quote above, Jennifer recalled how doctors and other medical professionals were dehumanizing and treated her similarly to how a person might examine a circus sideshow or other medical curiosity.

> I expect, in a medical environment, my body, my disability, and my impairments to be scrutinized. I expect everything to be put under a microscope. I remember when I was a kid, I had doctors come into my room with their residents and ask me to stick out my tongue, so that they could see the tremors in my tongue [a common symptoms for Jennifer's disability]. I didn't understand what they were doing at that young age (Jennifer).

The impact of having their bodies studied and violated at such a young age left a lasting impression on the women, including low feelings of both body autonomy and body-esteem as well as maladaptive coping strategies (e.g., hypersexualization). The women further described instances in the interviews where they felt reduced to a diagnosis or a disability type by medical doctors, which contributed to feelings of low self-worth, low self-esteem and body-esteem. This next quote describes the feelings of one of the participants in visiting doctors and specialists.

> You're so reduced to diagnosis. It's almost like saying, "you're absolutely nothing." It's almost hard to make sense of what you're supposed to be. It's hard to not get caught up in all of that because you have a lot of medical visits. I mean, if every medical visit you are being reduced to a diagnosis than how do you see yourself as a person sometimes? You [start to] see [yourself as] a series of complications (Mariam).

Mariam's description captures important considerations that highlight the impact of Medical Trauma on an individual's sense of self and their identity. She describes how repeated exposures to a medical model of understanding disability makes her feel as if she does not exist in any other meaningful way except as a medical mistake or a diagnosis to be studied and gawked at as a tool for learning about diseases/disabilities. She elaborates that for persons trained in the "objective" medical model of healthcare, "It's really so hard to see people as people". Another participant, Kelly, who despite living in another country (Australia) with a different medical system, describes very similar experiences.

> I definitely felt like the doctors always just viewed me as a person that was a medical condition and they were more interested in that than actually who I was.
> I have had some bad experiences in the past. I mostly find that hospitals are very boring and very depressing places. They're very lonely. The hospitals where I live [Australia], most of the patients are elderly. I used to see a doctor for my SMA every year. I got sick of being their guinea pig. In the end, I've given up on it because there's always something else they want to look at. That can be very annoying and stressful (Kelly).

Kelly describes feeling like a "guinea pig" to be tested on not for her benefit, but for the benefit of the doctors. She also discusses how being in a hospital with mostly elderly people whom she cannot relate to makes her feel lonely, isolated and different from others. Being dehumanized, or literally compared to a guinea pig, was the primary complaint most of the participants had while receiving treatment from doctors and other healthcare professionals.

> As if as a person with disability, you didn't face enough. Then, if you receive enough messages that you're not good enough on top of that…Medical professionals are telling you you're not perfect enough from a health perspective either. That's just one more added thing. I think that a lot of times medical professionals don't see you as people at all. Even if you tell them about a social event or a life [outside of your disability symptoms] in general, they're almost shocked or surprised that you managed to have friends or something. It's the tone (Mariam).

The resulting outcome from these repeated experiences was to avoid seeing doctors and other healthcare professionals. For example, Kelly explains how: "I definitely felt like the doctors

were always just viewed me as a person that was a [series of] medical conditions and they were more interested in those than actually who I was." Related, Jess describes:

> I don't even like going to the doctors. I haven't seen my doctor [in a long time, only] to get my medications. If I don't have to go, then I don't go. You go in and you're in pain. They [the doctors] are just looking at what the patient has and they list all the textbook definitions. There is no thought into this person [the patient] or interest in "Look! Oh! She is in school." There is no thought into her life or other parts. Then again, they are just doing their job and trying to get through as quickly as possible but I do understand that feeling of feeling like an object (Jess).

Being objectified by medical professionals had a significant impact on the women interviewed. Another related description that participants spoke of was feeling as if they were on display, particularly in the context of weight management practices. For Kendra, she discussed how she feels degraded when she goes to her doctor's office to get weighed.

> I feel like the spectacle when getting on a scale. Then [the questions and comments of the healthcare practitioner], "Can you stand on the scale? Can you stand 15 seconds longer? This is really hard. You should go to a special doctor." It's just the anxiety that comes from actual experience and makes it impossible to negotiate any of the ableism that would already come. Then, any sort of medical feedback and I would probably end up laying down somewhere in the waiting room and dying (Kendra).

Related to the theme of body autonomy, Kendra further states that once she felt able to dictate her own medical decisions, she has not let any medical professional weigh her, which speaks to the emotional impact this has had on her. She explains, "I have never let a health care professional weigh me as a grown up. As soon as I had autonomy over when I get weighed and when I don't get weighed, I didn't get weighed anymore." For many of the women, receiving medical and other health support services resembled a war zone of sorts. A war zone where they had little to no input with regards to their treatment, body autonomy, or their general participation in the "war". Rather, as children, they were a part of this medical system that attempted to treat, rehabilitate, or help them "for their own good". In addition, they were constantly on guard for mistreatment, accessibility barriers, and negative stereotypical attitudes

of disabled people by medical professionals. Furthermore, because most of the women had chronic, longstanding disabilities, they were expert patients yet often did not witness any immediate health benefits from their long history of medical procedures and visits. As a result, avoidance of doctors and specialists was a common response for women interviewed.

Inaccessible Treatment

In addition to the negative experiences the majority of the participants described with interacting with their primary healthcare providers, women also spoke about how inaccessible treatment created undue stress and medical trauma for them. In the first quote below, Hannah discusses how her own desperation for helped caused her to go into financial debt. She recalls: "The initial visit was $900, then $150-$250 a visit after that. It's not something that I could afford. But I remember at that time, I reached a breaking point and I just really wanted help. I just financially made the sacrifice." For Hannah, due to a general lack of free services, such as physiotherapy and dieticians, she was forced to pay out-of-pocket at great sacrifice to her well-being. In this subcategory, inaccessible treatment could include physical barriers, such as no wheelchair access into a building or no accessible washroom on the premises, or limited access to support persons, such as attendants to assist in transferring or activities like eating. Again and again, in all of the interviews with women who required attendant care services, the lack of needed hours and unavailability of properly trained staff was a consistent theme.

> Quality attendant care is critical for the health and well-being of people with disabilities. I don't know if we put enough resources in that nor that we want to. I think that the biggest problem is that our systems are designed for people with disabilities from the perspective of an able-bodied person. It's designed for us opposed to with us. I know it all comes down to cost. You have the wrong people in decision-making powers that are still sort of holding on to these outdated ideologies that providing service is a privilege (Mariam).

Other examples of inaccessible treatment included a lack of inclusion of differing abilities into programming, such as designing an exercise class for persons who can walk, run, jump or group therapy without support persons or technologies to assist in writing activities. Although many of these examples did not intentionally exclude women with physical disabilities, by not incorporating a lens that accommodates for disabled bodies, the resulting impact of isolation and frustration is inevitable. Michelle, who was diagnosed with anorexia in her mid-twenties, recalls her hesitation with receiving treatment for her eating disorder. During the interview, she listed off a number of reasons why she could not go to an eating disorder treatment centre and the majority of reasons appear to be related to inaccessible treatment.

> I need help with going to the bathroom and with cutting up food. Also, little things like, I need a straw to drink. I can't write or draw or do the things that maybe they might do in treatment. I just feel that it would just be another reason that I'm different and I don't fit with everybody else (Michelle).

Michelle elaborates that not having all of her disability needs met in a given context such as an eating disorder treatment centre, which is not organized to accommodate women with disabilities, contributes to her feelings of difference from other people. She discusses how this difference, or needing special accommodations, makes her feel like she doesn't fit in with everyone else. In other words, she is made to feel like an outsider or an 'other', which further contributes to low-self worth. In response to her therapist's recommendation that she receive inpatient treatment for her eating disorder, Michelle responds with the following:

> My therapist said, "Well, this is the point where we usually say you should look into inpatient treatment through a hospital." I didn't want to do that at all. I've always said that I'd rather be shot in the head then go to some treatment centre. So, I gained some weight and was able to get my period back. Without that [threat], I probably would have slipped back. It was good that someone was able to say this is the time you need to really work on it (Michelle).

In Michelle's situation, she was fortunate to receive individual therapy for treatment of her eating disorder. As described, Michelle demonstrates powerful resistance to the idea of receiving treatment due to her disability-specific needs and feelings of being different than the other patients. Ambivalence and outright resistance towards treatment is common for women with eating disorders in general. However, for women with physical disabilities, this resistance can be amplified by the idea of not being accommodated or being 'different' from the other girls. Some of the other research participants spoke of simply avoiding any treatment or support altogether.

> I wasn't officially diagnosed because I refused to go to the doctor. I was always afraid they would throw me in the eating disorder clinic. But I had done everything pretty much in my power to avoid ever being officially diagnosed. I remember at that time of my life, I thought I wasn't sick enough to be considered anorexic because according to the BMI pages, my BMI wasn't underweight. I thought if I went and saw someone they would think I was lying. That I didn't really have an eating disorder, I was just looking for attention. I didn't want the other girls to go: "Ew! She's so fat!" (Kelly).

In the above quote, Kelly discussed how she felt that her disordered eating symptoms did not fit with what she expected of other girls in an eating disorder clinic. Specifically, she was concerned about being too fat for an eating disorder treatment centre. It should be noted that persons with physical disabilities like Kelly's often do not conform to guidelines recommended by most Body Mass Index (BMI) charts. In addition, Kelly spoke previously about other ways in which she avoids doctors and medical treatment due to past negative experiences and her opinion that it was not helpful. The distinction between benefits and cost of medical treatment and follow up was a frequent theme in the interviews. For many women living with chronic disabilities, the benefit of ongoing medical treatment did not surpass the perceived high costs of navigating a complicated and inaccessible system and dealing with feelings associated with medical objectification and trauma.

Study 2 Discussion

The main objective of Study 2 was to further understand the experience of disordered eating in women with physical disabilities, including motivations, its manifestations, perceptions of differences in comparison to women without disabilities as well as any support/treatment experiences. A grounded theory approach using methodical hermeneutics was used to analyze eleven interviews of physically disabled women selected based on their elevated disordered eating scores in Study 1. Participants were asked how their eating has been these days and follow up questions included understanding how participants felt their physical disability impacted their eating and body satisfaction. The core category that emerged was named Surviving And Thriving In A World That Was Not Meant For Disability And Difference. It captured the feeling and experiences of being different that all the disabled women described in addition to the ways they reacted, coped, and even thrived in an inaccessible/inhospitable environment. Within these findings, disordered eating was experienced as different in comparison to nondisabled women, particularly in terms of its manifestation, etiology, and treatment/prevention, and disordered eating was used as a method of coping in response to feelings/experiences of being different. In many ways, disordered eating represented another instance for disabled women in which they were set apart from other women. Their eating behaviours were described as a Nutritional Purgatory because women felt that they did not quite fit the stereotype of a typical women with disordered eating yet they also did not feel like 'normal' eaters. However, as will be discussed further below, disordered eating was only a part of the story that the women described. The findings highlight the complexity disabled women experience living with bodies that do not conform to social standards and

norms related to mobility, functionality, appearance and attractiveness, productivity, and social desirability.

The core category identified how physically disabled women felt different or apart from other women due to their disability. Women reported that they felt set apart in terms of disordered eating and body image in three ways: 1) their physical functioning and mobility, 2) their physical appearance, attractiveness and desirability, and 3) their social value and acceptance. Themes related to feeling different and struggling to fit in have been further documented in other populations of disabled individuals, including children and youth (Lambert & Keogh, 2015) and men with upper limb prostheses (Saradjian, Thompson, & Datta, 2008). However, feeling different or set apart from other people within society is not a novel experience for persons with disabilities. In fact, it is one of the more common complaints of persons seeking mental health therapy (e.g., Mark, Barber, & Crits-Cristoph, 2003). It's been studied in young people in foster care (Madigan, Quayle, Cossar & Paton, 2013), elderly persons (Weiss, Sassenberg, & Freund, 2013), women experiencing menopause (Moran & Keating, 1992), and racialized persons (Barbas, 2000). Other research has indicated that feeling like an outsider can contribute to feelings of low self-worth (Wilhelm, 2006) and isolation and hopelessness (Zerbe, 1993). In the next section, I will review in detail various ways that women with disabilities felt different, how that impacted their health and eating, and the implications as grounded in other scholarly research.

In the first subcategory, Functional Differences, disabled women's difficulties maintaining health was a common theme. Similar to previous research, women in the current study also reported difficulties engaging in physical activity due to mobility problems, secondary health conditions (e.g., chronic pain), and physical accessibility barriers (Fox,

Witten, & Lullo, 2014). However, the findings in Study 2 offer new understandings to the literature as to the reasons why disabled women experience difficulties maintaining optimum health and weight. For one, the widespread societal belief that disability is incompatible with good health has had significant impact on women's health practices. Women described the impact of constant messages received that engaging in health promoting behaviours was pointless as it could never offset the negative health implications of living with a physical disability. Furthermore, women explained that the lack of research, knowledge and health guidelines for disabled persons served to only reinforce the belief that there efforts were futile.

A second novel contribution of the current research into the increased risk for obesity in disabled women was the role of dependency and personal support/caregiving on disabled women's health and their engagement of health promoting behaviours. These findings align with another qualitative study that highlighted how supportive others positively and negatively impacted their eating and wellness plans (Mudge, Stretton, & Kayes, 2014). Women in the current study discussed how challenging it was for them to prepare meals and eat healthy, engage in medically appropriate/accessible physical activity, and follow doctor prescribed health recommendations, when they depended on limited personal support hours. The majority of past research has focused mostly on how environmental inaccessibility of living spaces and food services (Barnes et al., 2012) and financial limitations (Webber, Sobal, & Dollahite, 2007) impacted food and eating. However, the current study highlights how access to support services was also a major concern. Most of the time, women reported that they barely had enough sanctioned hours to fulfill basic life sustaining activities (e.g., toileting, transferring out of bed, etc.). There was also an additional psychological toll of relying on others that contributed to women wanting to have more privacy at the cost of neglecting other health promoting activities.

For instance, women discussed how disordered eating behaviours were often motivated by efforts to maintain bodily autonomy or a feeling of control in an often uncontrollable situation. Although much previous research has been done on psychological impact of caregiving on the caregiver, the current study highlights the need for more research from the perspective of the consumer receiving care as it likely has a multifaceted impact beyond risk for disordered eating and body dissatisfaction.

Alternatively, the functional differences between disabled and nondisabled women also partially explained the etiology of their disordered eating behaviours. Disabled women discussed how the consequences for weight gain as a physically disabled person were magnified and could result in a significant loss of mobility, independence and quality of life. These findings align closely with that of Silber, Shaer, & Atkins (1999), where participants in that study were triggered to engage in food restriction by physician recommendations to lose weight to maintain their mobility. For the women in Study 2 who described having significant eating disorders, the perceived overemphasis on maintaining mobility and functionality further resulted in medical professionals overlooking their disordered eating and attributing any weight loss either to secondary health consequences of their disability or appropriate and healthy efforts to lose weight. As a result, disabled women struggling with eating disorder symptomatology in this study were not provided treatment or support. Webb's (2009) case study about a young woman with cerebral palsy and anorexia nervosa describes a similar example where medical professionals are almost overwhelmed with the complexity of her physical symptoms. Moreover, other scholars have documented the phenomenon where a single trait or medical condition can overshadow other difficulties or struggles in the area of weight stigma (Brownwell, Puhl, Schwartz, & Rudd, 2005) and within the elderly population (Skirbekk

& Nortvedt, 2012). The phenomenon closely resembles that of diagnostic overshadowing, where mental health explanations dominate over physical symptoms (Nash, 2013). The implications, as outlined in the current study, are severe and can include misdiagnosis, inappropriate treatment and overall worsened health.

The second subcategory explored the theme of embodiment differences for disabled women. Participants discussed how their body image is negatively impacted by the social devaluation and perceived undesirability of disabled bodies. In women without disabilities, media representations of ultra-thin bodies have been linked to body dissatisfaction, disordered eating and low self-esteem (Grabe et al., 2008; Groesz, Levine, & Murnen, 2002). Further, body-checking behaviours, such as frequently weighing oneself and comparing one's shape with the figure of others, have been studied extensively in nondisabled women with and without eating disorders as related to body dissatisfaction (Grilo et al., 2005; Haase, Mountford, & Waller, 2011). However, little was known prior to the present research regarding how these findings may generalize in women with physical disabilities. The current study has highlighted a few important differences between disabled and nondisabled women. For one, disabled women reported checking and comparing their bodies to women without disabilities who are considered the 'healthy norm', regardless of their weight/shape. Secondly, in terms of media influence, disabled women explained how the complete absence of representation of physical disability negatively impacted their body esteem. Zitzelsberger's (2005) uses the descriptor 'Invisible' when summarizing the experiences of physically disabled women and beauty, which also captures the narratives found in Study 2 interviews of being so far removed from the societal scale of attractiveness that they were completely discounted. Disabled women report being paradoxically very much on display in socially accepted disability narratives (e.g., as a

patient in a medical facility) and simultaneously invisible in terms of traditional narratives of femininity (e.g., within media, as potential dating partners).

Relatedly, disabled women in the current study expressed difficulties with dating and sexual esteem, which is consistent with previous literature (Taleporos & McCabe, 2003). Oftentimes, these difficulties are attributed in the literature to factors such as inexperience and lack of sexual education (Curry et al., 2001), medical and health-related issues (Howland & Rintala, 20001), and environmental challenges associated with inaccessibility (Rintala et al., 1997). Less research has examined how an interaction between individual factors (e.g., body esteem) and social factors, such as a societal preference for nondisabled bodies, can impact dating and relationships for physically disabled women. One of the novel contributions of the current study was its exploration of how medical objectification of disabled bodies impacts embodiment and body image, and thus, affected eating. Women discussed how a lifetime of medical trauma, dehumanization and being treated like a medical diagnosis contributed to low body-esteem. Recent clinical research supports that invalidation through medical mistreatment/trauma is widespread concern in medical settings (Hassouneh-Phillips, McNeff, Powers, & Curry, 2005). Rice and colleagues (2003) further describes how the language of medical professionals can carry strong implications. For instance, in both the current study and in Rice's work (2014), women explained that descriptors such as disfigured and deformed contributed to feelings of body shame and worthlessness. Rice (2014) later theorizes that early experiences of medical dehumanization have a similar impact on women as childhood sexual abuse. Given the past links between sexual abuse and increased risk for eating disorders, medical trauma may well be an unexplored link between physical disability and eating disorder symptoms.

The third subcategory, Social Differences, examined how a widespread societal devaluation of disabled people and disabled bodies contributed to feelings of low self-worth, discrimination, social difficulties and isolation, and increased rates of abuse. For disabled women interviewed, puberty was a particularly vulnerable time period in terms of developing symptoms of disordered eating. Other scholars have also written about the importance of puberty in the development of eating disorders and body dissatisfaction (Klump, 2013) as well as other mental health problems (Brody, 1997). Similar findings for eating disorder risk have been linked to puberty for women with disabilities (Smith et al., 2008). Rice (2015) theorizes that puberty represents a 'sexual spectacle' where both sociocultural and biological factors converge in creating circumstantial pressures of what it means to become a woman. For women with physical disabilities, similar to those without disabilities, puberty represented a confusing time period where appearance and sexuality became suddenly linked to social acceptance. Unfortunately, for the women in the current study, it was also the time when they became most aware of their social status as disabled women as asexual and genderless. As a result, many became concerned with their physical appearance and their romantic prospects and turned to strategies such as weight loss to ameliorate the negative impact of their disability.

With regards to disordered eating, the current study speaks to how the combined impact of ableism and weight stigma can have a detrimental effect for disabled women. Persons of larger bodies are frequently stigmatized, oppressed, and socially excluded (Friedman, Ashmore, & Applegate, 2008). Fat people are also subject to medicalization, cure-all/prevention narratives, and discrimination often justified by perceptions of medical and economic burden (Sobal, 1995), just like those with physical disabilities. Interestingly, very few studies or conceptual analyses to date have examined this important intersection between ableism and

weight stigma. The weight stigma (i.e., Health At Every Size) movement has extensively documented how the presence of fat and overweight status does not always correlate with health and fitness (e.g., Bacon, 2010), which essentially distances fat people from assumptions of poor health, inactivity, and functional disability. On the other hand, women interviewed in the current study feared the social stigma attached to being both fat and disabled, particularly because of judgments that they somehow caused their disability through weight gain. Within a current cultural shift away from promoting thin bodies and towards the promotion of health and fitness (Roosen & Mills, 2016), both movements could benefit from increased societal acceptance of diverse bodies, regardless of health and fitness level, ability, perceived productivity, and/or size.

The findings in the current study also highlighted a widespread problem with caregiver abuse. Disabled women interviewed described that their relationships with caregivers as not just strained but were also characterized by frequent experiences of fear and criticism, particularly in regards to weight management and reducing the burden of care. In many ways, Study 2's findings echo those of previous studies that unfortunately found a lack of awareness, research, and support services directed towards the unique needs of disabled women experiencing caregiver abuse (Frantz, Carey, & Bryen, 2006; Nosek et al., 1997). Most women in the current study did not name their experiences as abusive but rather understood them as part of a required compromise or a normal condition of having to rely on attendant care services/assistance from family. These findings may help explain why obtaining statistics for abuse rates in the disability community is so challenging. Other scholars have estimated that abuse rates could be as high as 70% at some point in the lives of adult disabled women (Stimpson & Best, 1991). However, more research is needed as well as a general societal prioritization towards the betterment of the

lives of disabled women. Study 2 also speaks to the need for increased funding for support workers as well as training initiatives for caregivers, particularly training that would address the widespread body shaming that occurs for disabled women and contributes to increased disordered eating and decreased self-worth.

Another main finding in the qualitative research data revealed that women with disabilities in the study had diverse ways of responding to the feelings and experiences of being different in a society that does not accommodate disability and difference. In this context, food and disordered eating were understood as tools for responding to these differences and their associated consequences (e.g., social isolation, health problems, discrimination) in efforts to help an individual survive, and oftentimes thrive, in an unaccommodating environment. The current findings offer a useful framework for better understanding not only disordered eating but other seemingly pathological responses (e.g., depression, body dissatisfaction, low self-esteem) that have been highlighted in previous research as vulnerabilities for physically disabled persons. The findings also align well with recent research that outlines how people respond to threats of social rejection, ostacism and discrimination (Richman & Leary, 2009). In their multimotive model, Richman and Leary explain that after experiencing a threat to social acceptance and belonging, persons respond immediately with lowered self-esteem and negative affect. Then, following initial reactions, responses to the threat (e.g., avoidance, impaired self-regulation, seeking alternate sources of support, anger) are impacted by both their interpretation of the event as well as additional relational, contextual, and dispositional factors. Similarly, Study 2 findings uncover an equally complex set of responses from participants to related experiences of social threat that shifted by and within individuals. However, the current findings differ from that of Richman & Leary in that participants experienced not only threats

to social belongingness, but also threats to their health, well-being, and their very survival. Social rejection from a caregiver could make the difference between eating or not eating on that particular day. Below, I will further explore each of these reactions to an unaccommodating environment and discuss how the findings relate to literature in psychological coping, eating disorders, rehabilitation and critical disability studies.

Women spoke about how they felt more adept at coping the longer they lived as a person with a disability. Here, positive coping did not necessarily mean that they more successfully adapted to their physical limitations, as is often described in psychological literature (e.g., Livneh & Wilson, 2003). Rather, for many of the women, coping represented growing self-confidence and body acceptance even in direct opposition to societal messages of physical disability as dysfunction, undesirability, and burdensome. For many of the women, surviving and thriving equated to living their lives even in settings where they were unexpected or not accommodated.

Traditional narratives of coping with a disability are wrought with issues that negatively impacted disabled women's sense of self and social roles in the current study. Disability studies scholars discuss how the 'overcoming narrative' – a heroic disabled person who has against all odds becomes a successful person – is actually prejudicial, oppressive and disempowering as it defines disability as a personal defect that must be compensated for (Garland-Thomson, 2005). Others have theorized that an unaccommodating and oftentimes hostile environment for disabled people has contributed to the emergence of the "super-crip" (Titchkosky, 2007). The "super crip" overcomes her disability so well that she 'passes' as ablebodied (MacDougall, 2006). Within a cultural context that promotes independence, productivity, and bodily perfection, the "super crip" as well as the overcoming narrative become the only socially

acceptable stories of disability (McRuer, 2002). However, these embodiments leave no room for experiences of negative emotions and simply being human (Linton, 2006). It also means that ordinary disabled people are made to feel like failures if they fail to live up to that extraordinary standard (Nelson, 1994), as was felt by some of the participants in Study 2. According to Swartz and Watermeyer (2008), "The idealized, mythic valuing of the perfect body, with its associations of personal virtue, carries its counterpoint with the denigration of persons with different bodies" (p. 189). Within this cultural context, it then becomes understandable that disordered eating behaviours and other appearance modification strategies were used by participants to overcome their disability in order to be successful and fully accepted in society.

Within the cultural promotion of overcoming one's disability, there is also a push to resist becoming too dependent (i.e., too burdensome, too disabled). Women in the study reported that they coped with feelings of powerlessness that they experienced in many areas of their lives by increasing internal feelings of control through depending solely on themselves (wherever possible) in addition to rigidly managing other aspects of their lives, such as eating and weight. This finding is consistent with other studies on physical disabled populations that report distress over loss of bodily autonomy and independence (Michon et al., 1995). Further, qualitative research on eating disorders in women with physical disabilities corroborates reports that women attributed their food issues to a need for increased control (Silber, Shaer, & Atkins, 1999; Webb, Morgan, & Lacey, 2009). In fact, increasing overall feelings of control is a well-documented motivation for women without disabilities who have eating disorders. According to Cognitive Behavioural Models of eating disorders, a major component of recovery is supporting persons with eating issues to relinquish that control through decreasing rigidity in thinking and increasing their overall intolerance for uncertainty (Garner & Garfinkel, 1997). In

the case of physical disability and other prescribed social roles (i.e., woman, mother, etc.), recovery also may require active challenging of cultural ideals that prize independence and overcoming narratives at the expense of personal well-being and the need for personal care assistance (Linton, 2006).

Alternately, participants also discussed coping through the intentional decision to give up on any efforts to control. Certainly, there are adaptive advantages to accepting situations that cannot be changed. Literature demonstrating the effectiveness of Acceptance and Commitment Therapy (ACT) in reducing psychological distress can attest to the benefits of this important psychological skill (Hayes, Luoma, Bond, Masuda, & Lillis, 2006). According to ACT theorists, the root of suffering stems not from life stress and pain, but rather from misguided efforts to control things which cannot be controlled (e.g., emotional responses, chronic pain, body weight/eating) (Hayes, Strosahl & Wilson, 2012). Studies demonstrating the effectiveness of ACT for the treatment of eating disorders (Manlick, Cochran, & Koon, 2013) and chronic pain (Wetherell et al., 2011) suggest that the coping strategy of surrendering control may be particularly helpful for those with physical disabilities who often experience similar circumstances. However, for some participants in the study, their decision to accept their circumstances stemmed from a place of trying to survive following burn out. In these cases, their presentation seemed to resemble that of a depressive state or that of learned helplessness. Past studies have further supported that as persons with disabilities make unsuccessful attempts to control their environment, they come to view negative outcomes as inevitable and subsequently discontinue efforts (e.g., traveling with a disability: Lee, Agarwal, & Kim, 2012). As with all of the coping responses reported by women with disabilities in the current study, relinquishing the need to control one's surroundings and body could be adaptive and

maladaptive, depending on the context, and both experiences contributed to disordered eating (e.g., binge eating or dietary control).

Another coping strategy that was used universally across participants was the use of food and eating as a tool to regulate emotions. As previously discussed, for some that included rigid control of food intake. However, most participants in the current study discussed how they engaged in frequent emotional or binge eating. The current study is the first to explore the experience of binge eating and emotional eating from the perspectives of physically disabled women. Similar to participant accounts, eating pleasurable foods is perceived to evoke positive emotions and reduce negative emotions (Lynch, Everingham, Dubitzky, Hartman, & Kasser, 2000). Studies have shown that repeated consumption of high sugar/fat food can impact the dopamine signaling in the brain, resulting in abnormally sustained stimulation of the reward system similar to drug abuse (Bello & Hajnal, 2010). An increasingly influential explanatory model of obesity is that overeating, binge eating, and obesity are caused by an addiction to food (Brownell & Gold, 2012; Davis & Carter, 2009). For disabled individuals, food and binge eating can be a particularly potent "drug of choice". Many interviewed had strong associations between eating pleasurable foods following painful and traumatic medical procedures and subsequently, carried those associations into adulthood. Some participants in the current study have further highlighted that oftentimes alternate forms of emotion regulation common in nondisabled individuals can be off limits for disabled persons (e.g., physical activity, impulsive shopping) and as a result, food can become a readily accessible option.

Another common theme found in women with disabilities in response to difference was finding support and community. It was a consistent theme across participants that aided them in surviving and thriving in often inaccessible/exclusionary environments. Past research has

demonstrated the benefits of positive social support across a number of health and mental health outcomes in persons with disabilities (Muller, Peter, Cieza, & Geyh, 2012). The findings of the current study further suggest that support from other disabled persons may be integral in promoting self- and body-acceptance as a marginalized person. It is well-known that peer support can also decrease feelings of isolation for members living with similar challenges or health symptoms (e.g., Salick & Auerbach, 2006). In crip theory, which critiques the concept of normativity and celebrates disability as a cultural group, seeking not only support, but solidarity with other socially marginalized disabled people is crucial to activism and acceptance through pride and resistance (McRuer, 2006). The current findings further speak to the importance of receiving social support as a protective factor in disordered eating and body dissatisfaction. However, the quality of social support was also important. For instance, in one study of disabled women, poor or inadequate support resulted in unhealthy eating (Mudge, Stretton, & Kayes, 2014). Similarly, women in the current study reported that poor personal support resulted in high stress and difficulties eating healthy. In addition, women in the current study explained that eating out in restaurants was an important social activity due to its easy access, but simultaneously contributed to weight gain and the subsequent reliance of chronic dieting.

Another source of support that had an unexpectedly powerful impact on body-esteem and disordered eating was intimacy with men. The majority of women in the study described how acceptance of their bodies, including their physical disability, emerged once they were accepted by an intimate partner. Similar findings were reported by couples post breast cancer treatment (Loaring, Larkin, Shaw & Flowers, 2015). Breast cancer, understood as a crisis to women's body image, impacted the couple's sexual intimacy and communication as they renegotiated health concerns and what the author's refer to as 'the altered body'. Framing these

negotiations under a relational lens highlights how communication and acceptance of the other can impact body image and satisfaction. The current findings also highlight the strength of normative expectations of female bodies and the power of gender roles and sexual scripts (Gagnon & Simon, 1973). For physically disabled women, who are often viewed as genderless and asexual (Curry et al., 2009), the allure of seeking validation through male attention, culminating into a successful, 'normal' relationship, may be even more pronounced. For some in the current study, specifically finding an intimate relationship with an able-bodied man was the ultimate measure of success and signified that they were not, as society dictates, undesirable and unlovable.

Accessing inclusive spaces was important for disabled women seeking support for healthy living and mental health wellness. Similar to previous research (e.g., Odette et al., 2003), disabled women in the current study faced tremendous barriers in accessing healthy living resources, including but not limited to financial costs, inaccessible buildings, transportation issues, and limited staff expertise in matters related to physical disability. A surprising finding in the current study was the high incidence of attitudinal barriers women described experiencing when navigating supports, including presumptions of asexuality, ignorance of mental health issues, and frequent experiences of patronization. Olkin (2001), who researches psychotherapy and disability, reports that many therapists inaccurately believe that they are immune to bias towards matters of disability. However, past studies have shown that up to 75% of therapists view physical disability as a personal tragedy and reported difficulties 'seeing past' their disabled client's wheelchairs or other mobility devices (Parkinson, 2006). Consistent with Study 2 findings, these therapist beliefs can unintentionally leave clients feeling misunderstood (McKenzie, 1992), stigmatized (Oliver, 1996), as well as wary of psychological

services (Reeve, 2002). These findings help illuminate the possible disconnect between high prevalence rates of disordered eating in disabled women and low use of support services.

Many women in the study responded to feeling different by internalizing the problem of difference, resulting in efforts to compensate as well as more psychological problems. Whereas past research framed high rates of depression in persons with physical disabilities as a natural consequence of one's body losing functionality and mobility (e.g., Livneh, 1986), the current study reframes depression as the result of living within an environment that does not fully include and/or accept disabled bodies and subsequently internalizing that lack of acceptance. In many ways, the current framework is more inclusive of individuals with congenital disabilities who did not lose their abilities and, as a result, have no reason to grieve. It also provides an alternate framework in comparison to highly contested medical model research that presumes lowered quality of life and psychological pathology inherent within the physically disabled person (Goodley & Lawthom, 2005).

Disabled women also internalized the problem of their disability by overcompensating as a method to minimize its impact. Although past research on body image disturbances have highlighted how disabled women will dress in fashionable clothing or alter their appearance in other ways to compensate for their disability and impress others (Watson, 1999; Young, Nosek, Foley, Rintala, Howland, & Bennett, 1994), no study to date has explored its impact on disordered eating and mental health. The current findings provide preliminary evidence that disabled women attempted to mitigate the negative social impact of their disability through dieting. Moreover, participants also tried to compensate the negative health impact of their disability through dieting. Despite the fact that the intention of healthy eating may appear to be a worthwhile goal, for many in the current study, it became rigid and unhealthy, crossing into

the spectrum of disordered eating. Further, for disabled women struggling with chronic pain in Study 2, their obsession with weight loss to minimize pain became psychologically damaging as they blamed themselves for their perceived suffering. Relatedly, a recent intervention study for eating disorders found that those who believed they had less personal control over their weight were more likely to be recovered than those who maintained that their weight was malleable (Laliberte, Balk, Tweed, Smith, & Ghai, 2014). Healthism, a cultural discourse of recent interest which upholds that people have ultimate control over their health through lifestyle choices and personal health should be the primary focus of well-being (see Brady, Gringras, & Aphramor, 2013 for a review), is a common societal belief that can negatively impact those who do not fit within the narrow parameters of what it means to be healthy, including physically disabled persons, those with chronic health conditions, and overweight/obese persons (Roosen & Mills, 2016). If healthiest practices and limited ideals of health (e.g., weight and physical activity focused) continue to be the dominant discourses in health promotion, disabled persons (as well as fat persons) will remain at-risk for secondary health conditions in addition to their misguided attempts to regain health through dietary restraint and other disordered eating behaviours.

The current findings were unique in their discussion of not only what contributed to the vulnerability and risk of disabled women but also factors that were protective and demonstrated empowerment in the disability community. For one, when women resisted socially defined ideals of health, they were able to strive towards healthy living within any limitations of their disability. Certainly, as mentioned previously, there were barriers and challenges, many of which were socially constructed. However, the women in the study displayed creativity and adaptability in their pursuits. Secondly, disabled women in the study found ways to tolerate,

accept, and even celebrate their bodies in the face of repeated messages that equate physical disability with undesirability, asexuality, and suffering. For some in Study 2, even though they may have had difficulties loving their bodies, particularly if they had various health problems or loss of physical functioning, they eventually came to a place of tolerance of their bodies, meaning they refrained from actively hating or harming themselves (e.g., starvation diets, purging behaviour). Research in eating disorder treatment similarly recommends that clients work towards a place of body tolerance as opposed to the much more psychologically threatening standpoint of body acceptance (Manlick, Cochran, & Coon, 2013). In addition, the current study results work to expand the body tolerance notion into difference aspects of body acceptance/tolerance. In other words, as described by disabled women, a person can accept their body in terms of its health and functionality and, at the same time, tolerate her appearance and weight.

The journey of self- and body-acceptance for disabled women was further aided for many in the current study by identifying proudly as a member of the disability community. This included acts such as aligning with the social model of disability, advocating for disability-based rights, embracing and owning differences defined by disability, resisting disability stereotypes, attributing positive attributes to disability, and celebrating disability/crip culture. Unfortunately, the benefits of such resistance-centered activities are amiss in most psychological research and treatment programs where the individual medical model of disability still reign (Kudlick, 2005). The current study is unique in its focus on both medical and social models of embodiment. After all, the social model of disability, with its focus on empowerment and reframing the problem of disability, has been quoted as quite literally saving the lives of disabled persons previously kept ashamed of their lives and their identities

(Chandler & Rice, 2013; Crow, 1996). Disability art/culture has also been credited in creating new understandings and, ultimately, greater acceptance for non-normative people and embodiment differences (Clare, 2001). Social and clinical implications from activist art can include greater reported self-empowerment by artists, increased awareness around accessibility and inclusion, and challenging ableist assumptions held by healthcare professionals (Rice, Chandler, Harrison, Liddiard, & Ferrari, 2015). Those with disabilities in another study reported that feelings of invisibility and being treated as incompetent by medical professionals were assuaged by their use of self-advocacy (de Vries et al., 2016). On the other hand, the more participants in the current study strived to distance from their disability and pass as 'normal', the more they acknowledged difficulties with body acceptance and disordered eating. This was particularly true for those participants with invisible disabilities who may feel less connected to the disability community.

Taken together, the current study provides a richer understanding into the experience of eating and body image for women with physical disabilities. More specifically, it explores the impact of being and feeling different from other women to health, psychological well-being, body satisfaction, eating, and relationships. The current study differs from other research on disordered eating and disability in that there is an emphasis on exploring both what contributes to disordered eating and mental health struggles and what factors can be protective. Moreover, these findings were understood as a complex collection of responses that were adaptive given the hostility of living in a world not meant for disability and difference. Under this model, almost all women interviewed explained that they engaged in the different behaviours or responses at one point or another in their lives for various reasons. Rather, participants differed only in the intensity of the behaviours and their understanding of how adaptive or maladaptive

(surviving vs. thriving) it was under the circumstances. These findings are in contrast with past medical scholarship that understands the disabled body as the source of deviance, deficiency, and psychological distress. As such, the current discussion borrowed from feminist and critical disability scholarship to better understand how social structures and beliefs about disability in a society contribute to disordered eating and mental health in physically disabled women.

In the current findings, although all participants had acknowledged experiencing nearly all of the feelings and reactions discussed, there were nonetheless some responses and trends that differed across participants that were more strongly associated with disordered eating, body dissatisfaction, and mental health problems. The greatest harm seemed to be connected with women internalizing societal messages that devalue disability as something that is undesirable, burdensome, problematic, and abnormal. Messages received, directly and indirectly, through family, peers, medical professionals, potential intimate partners, media, and through numerous experiences of being excluded, rejected and ignored, exacerbated feelings of difference and being an outsider. The consequences of internalized ableism on women's self-worth negatively impacted their health, advocacy and care, body satisfaction, and relationships. Moreover, an additional societal devaluation of obese bodies further exacerbated the negative impact given that disabled women feared becoming less mobile and more undesirable (i.e., more disabled). This was especially the case for those women who were dependent on unreliable or, in some cases, abusive caregivers and those women who felt pressure to lose weight from medical professionals due to chronic pain. In other words, the women who were the most vulnerable to the effects of having a mobility disability seemed to report more disordered eating out of a perceived necessity. Fat stigma combined with narrowly defined parameters surrounding health and well-being created a powerful motivation towards engaging in disordered eating,

particularly calorie restraint (viewed as the only solution for the inevitable weight gain of living with a mobility disability). The next section will further explore the clinical implications in the current set of studies through integrating the findings of Studies 1 and 2.

Discussion and Integration of Studies 1 and 2

The main objective of the current set of studies was to better understand the role of physical disability in the identification, manifestation and treatment of disordered eating in young women. Study 1 assessed the frequency and severity of disordered eating in a population of disabled women as well as the impact of perceived disability on symptoms of disordered eating and mental health; whereas Study 2 used qualitative methods to uncover the perceived role of physical disability on disordered eating based on the experiences of disabled women. A consistent finding of the present research, with regards to both qualitative and quantitative findings, was that greater negative impact ascribed to physical disability was associated with more experiences of disordered eating, mental health stress and health-related problems. However, the relationship between physical disability and health outcomes was anything but straightforward. In contrast to previous scholarship that assumes that greater functional disability is associated with increased psychosocial distress, a conclusion of the current research is that the meaning ascribed by an individual to her physical disability was more influential on one's eating and mental health than was the functional severity of disability. Further, the impact of that disability meaning differed both between and within participants at different points in their lives and even within moment-to-moment contexts. The model of coping with disability revealed by the current set of studies was more aligned with recent research that defines coping as temporally based and transient for persons with disabilities (Livneh, 2016). Furthermore, the meaning ascribed to disability tended to be informed by numerous sources including family, friends, personal values and broader cultural values as opposed to its functional severity only.

Women's accounts of living with a physical disability in an often inaccessible (in every sense of the word) world integrated scholarship from medicine/rehabilitation and psychology

(i.e., traditional models of coping), and feminist/critical disability studies (i.e., social models of disablement). The complexity of the current findings challenged traditional models of coping with physical disability that focus on grieving, crises, and loss. At the same time, social models of disablement also failed to completely capture the experiences recorded by disabled women in the current study. The social model has been critiqued by scholars for minimizing the intimate embodied experiences of disability, such as pleasure, pain, fragility, vulnerability and the meaning ascribed to disability and disablement (Clare, 2001; Valeras, 2010). According to Rice (2014), a more fitting lens for understanding the experiences of disabled women are body becoming and embodiment theories informed by feminist and disability studies. Through these models, the process of becoming disabled women is understood as dynamic, transient, and unpredictable; shaped both by individual psychologies and bodily functionalities interacting with social and cultural environments. It is through these lenses that disordered eating experiences are best understood for the disabled women in the current set of studies. Women experienced medical and physical differences that impacted their eating, which interacted (reciprocally) with non-accommodating environments that promoted cultural ideals of thinness, productivity, and able-bodied/normative embodiments.

The current set of studies adds a number of important findings to the literature on the relationship between disordered eating and physical disability. First of all, although the relationship is complex (as explored above), there does seem to be a protective value that accompanies having greater number of years living with a disability. Women who had lived longer with their disability reported comparatively less disordered eating, body dissatisfaction, mental health distress, health-related concerns, and social problems. Although past research has mostly oversimplified this finding as being related to ‘better coping’, the current study explored

in detail some of the reasons why more time spent as disabled translates to better psychosocial outcomes. All participants shared different narratives related to their "journey of acceptance" towards accepting themselves, their bodies and their identities as disabled women. Within those stories, women explained that they were able to find their own path, accept themselves better in the face of limiting societal messages, cope with health issues, adapt and thrive in a world that was frequently inaccessible, advocate for their right to take up space, find supportive others (particularly those who accepted them as disabled women), and understand themselves better. For many in the study, disordered eating and body image issues emerged in early adolescence and during a time when their physical disability increasingly differentiated them from their peers and other women. Attempts to ameliorate that sense of difference through disordered eating, although somewhat understandable, actually discouraged self-acceptance as well as acceptance by others as a disabled person who probably would never traditionally 'fit in' with their peers.

Second, the current findings suggest that the presence of active health problems, such as chronic fatigue and pain, was much more damaging on coping, disordered eating and mental health in comparison to disability status. Women with health problems in the current study seemed to be those who were most recently diagnosed with physical impairments. As a result, their perception of physical disability tended to match that of most individuals in Western society – that of catastrophe and suffering. It was difficult for these women to imagine a future with a disability that wasn't defined by limitation and pain. Further, women experiencing health problems were mostly experiencing chronic pain, which was unpredictable and prevented them from accomplishing important goals. Moreover, the recent cultural trend of taking control over personal health had a noticeably negative impact on women with health problems. Despite their

dogged determination to eat healthy and exercise, these women continued to experience chronic pain. The message received by these women from doctors, family members and others, is that they need to lose weight. In response, the women internalize their failure and, paradoxically, turn to food or inactivity in response to this frustrating situation.

Third, the experiences of women with physical disabilities in the current study have illuminated a greater understanding into the construct of body dissatisfaction and body image. Past research has suggested that body dissatisfaction in women with physical disabilities may reflect an accurate interpretation of their bodies in the context of a society that values beautiful, thin women. However, this interpretation represents an oversimplification that fails to consider how negative, limiting views of physical disability and physical differences (e.g., fatness) impact body image and embodiment. Women in the study discussed how their initial disappointment with their bodies' appearance and functionality was usually in comparison to those without disabilities. With time, women began owning their physical differences and challenging societal ideals that dictate beauty and devalue disability. Embracing their differences and their disability often evolved through relationships with others, developing community, and reframing the model of disability to a more positive one. However, the relationship between disability and body image was complex. For some, accepting their body and their disabilities shifted on a moment-to-moment basis. For others, they could never get to a place of full body acceptance and positivity, but were satisfied in their ability to tolerate their bodies, which meant they called a truce with their bodies and abstained from any harmful weight control behaviours. To accept their bodies, whether that entailed their body's physical function, appearance, or weight, in a physical, social and cultural space that devalues and

actively punishes disability, was both a psychologically taxing and difficult act as well as a culturally defiant act of resistance.

Fourth, the current studies explored how cultural values promoting health and fitness, and that equate those values with being thin, promote disordered eating and body dissatisfaction in physically disabled women. The vast majority of previous research on eating with physically disabled persons have been written in the interests of curbing the problem of obesity in this population due to its assumed negative impact on health and healthcare costs. Paradoxically, these mounting pressures to be as thin and fit as possible, which have infiltrated the agendas of many medical professionals, and educators are contributing to greater health problems, including disordered eating and obesity. The current studies have highlighted how the pressure to lose weight combined with a fear of obesity, due to its association with becoming burdensome for caregivers/family, create a perfect storm for eating disorder behaviours in attempts to lose weight. Not present in these medical narratives include how cultural preferences for independent, healthy, and nondisabled bodies can further feed these fears. Apprehension around caregiver mistreatment/abuse and fears of losing abilities/independence are common in the minds of disabled women, which can fuel a drive to lose weight.

Lastly, physically disabled women felt different from other women in terms of both their experiences of disordered eating as well as any possible prevention and treatment. Disabled women felt in limbo between healthy eaters and those with eating disorders (without disabilities). For them, they felt that they could not eat what would be considered ‘healthy’ for persons without disabilities, yet they were not ‘sick enough’ to meet criteria for an eating disorder. Regardless of the veracity of this claim, the meaning that they ascribed to this difference resulted in an almost self-fulfilling prophecy because disabled women subsequently

avoided treatment or disclosure of any eating concerns to medical professionals. Further, feeling different from nondisabled women and mistrusting of the potential benefits of seeking support resulted in self-made remedies for weight loss, mainly consisting of calorie restriction due to perceived limitations in physical activity. For instance, most in the study reported eating a set limit of calories per day (800-1000 calories) that was lower than what would be recommended for others. Each participant seemed to have her own justification for her caloric limit; however, these were rarely based in medically supported recommendations. In the absence of reliable support and information, combined with strong motivations to lose/maintain weight, disabled women were making recommendations for themselves that probably promoted increasingly disordered eating and its associated consequences (e.g., body dissatisfaction, weight gain, psychosocial distress). Conversely, conventional eating disorder treatments and recommendations based on research systematically excluded disabled women. Past experiences of medical trauma, reported by the majority of participants, further reinforced ideas around the futility of seeking medical support. Interestingly, the only exception where women were willing to seek professional support was for weight loss. Most of the participants shared that they would be motivated to receive support for weight loss (if it were specially geared towards physical disability) but not necessarily disordered eating, highlighting again the powerful converging impact of sizeism and ableism.

Clinical Implications and Future Directions

The current set of studies provides useful information regarding future directions and recommendations for the professional support of disabled women who also struggle with disordered eating. No study to date has examined the effectiveness of disordered eating interventions in disabled women; however, there has been some research on promoting healthy

living (e.g., eating, exercise, preventative medical care) in this population. These intervention studies have mainly examined the impact of workshops and group support group programs. Although the studies have each demonstrated some degree of success, particularly in terms of improvement of self-reported mood and health self-efficacy, most studies were unable to report significant behavioural changes among participants in terms of healthy eating or increased physical activity (King, Pomeranz, & Merton, 2014). The programs that were most successful seemed to apply a broader and holistic view of healthcare, providing participants with accessible healthcare spaces, healthcare professionals trained to work with disabled clients, and programs that promoted empowerment (Horner-Johnson, Drum, & Abdullah, 2011; Hughes, Nosek, Howland, Groff, & Mullen, 2003; Xenakis & Goldberg, 2010). In these studies, participants were provided both tools and support that resulted in decreasing the social disparity that limits access to healthcare and other support.

The current findings suggest that any intervention to reduce disordered eating and body dissatisfaction in disabled women would benefit from: 1) knowledgeable, disability-aware support persons, 2) an approach that provides accessible healthcare and actively reduces other social barriers to healthy living (i.e., access to adaptive gym equipment vs. recommendations to go to the gym), and 3) an approach that encourages a broad understanding of health and well-being that would fit the needs of physically disabled women (e.g., those who are sedentary, utilize attendant care, live in poverty, limited access to healthy foods, etc.). These recommendations are expanded upon below.

In the current set of studies, participants revealed that they often turned to unhealthy eating only after trying to seek support from dieticians and other healthcare professionals who were perceived as uncomfortable or uninformed in advising a person with a physical disability.

This finding underscores the limited exposure and training that many healthcare professionals have in working with clients with disabilities. However, in the case of dietary advice, psychoeducation related to general nutrition and the negative effects of dietary restriction that is relevant to nondisabled individuals would still be equally beneficial for disabled women and ought to be available. A lack of confidence communicated by professionals can reinforce beliefs disabled women have related to mistrust of medical interventions as well as their innate differences from other women, which can result in self-determined caloric restriction much lower than that of the minimum recommendation for able-bodied women. More research to inform disability-specific dietary and medical recommendations would assist healthcare professionals in conveying confidence to clients and subsequently challenge these preset beliefs around diet and nutrition. In addition, a general attitudinal shift in working with disabled clients is needed that can reduce the perceived fear and awkwardness experienced by disabled women in the study when interacting with healthcare professionals.

Health-At Every-Size (HAES) may provide a useful framework for supporting weight management and eating issues in women with disabilities. Research has found that traditional weight-loss methods (e.g., calorie restricting diets and exercise) have demonstrated limited effectiveness in improving health (Berg, 1995; Miller & Linderman, 1997) and can lead to the negative mental health outcomes associated with disordered eating (Polivy, 1996). As reviewed in the current findings, women with disabilities seem particularly susceptible to the allure of dieting for weight management because of past experiences with weight gain in addition to limited support from healthcare professionals. In contrast to traditional weight-loss methods, HAES advocates for a non-dieting approach to weight maintenance and the promotion of healthy behaviours, such as eating nutrient-dense foods and getting regular accessible activity,

without the pressure to lose weight (Miller & Jacob, 2001). The HAES approach responds to the need to help women engage in health-promoting behaviours while also addressing issues of body dissatisfaction, disordered eating, and other psychological factors associated with eating (e.g., depression, emotional eating), which promotes long-lasting lifestyle changes. Research supporting the efficacy of HAES approaches has been promising and health scholars have called for its implementation in general medical practices, replacing ineffective and potentially hazardous traditional weight-loss methods (Miller & Jacob, 2001). HAES intervention studies have demonstrated reduced psychological distress and improved quality of life (Goodrick et al.,1998), decreased binge eating and disordered eating (Polivy & Herman, 1992), and even sustained weight-loss for up to two years following the intervention (Sbrocco et al., 1999).

Although HAES appears to be an effective model of care, there a few considerations that warrant attention if it were to be successfully applied to a disabled population. For one, the findings in the current set of studies suggest that a powerful barrier to health for disabled women was the belief that disabled bodies cannot achieve health and fitness. In fact, women interviewed reported that movements similar to HAES have left them feeling further excluded because their specific needs were not addressed and often the recommendations could not be applied to them (e.g., physical activity limitations). HAES would benefit from an expanded definition of health in order to be more inclusive of those with mobility impairments, which would help prevent further disengagement from members of the disability community. Second, the HAES movement has been criticized for lacking awareness of greater sociocultural influences that impact health, food choices and physical activity (Brady, Gingras, & Aphramor, 2013). For disabled persons who struggle with poverty, employment, limited support and attendant care services, food scarcity, and general inaccessibility, any health intervention would

need to carefully consider each of these barriers if it were to succeed in this population. Finally, intervention studies need to be conducted with a disabled population to test some of these suggested adaptations and explore further how this model can be developed more effectively for women with disabilities.

An important finding in the current set of studies was the high occurrences of medical trauma and other mistreatment by support persons experienced by physically disabled women. Similar to research outlining common trauma responses (e.g., childhood abuse: Bensimon, 2012), disabled women in the current study recalled experiencing symptoms of hyperarousal, anxiety, panic, and re-experiencing (i.e., flashbacks) when inadvertently triggered by routine medical procedures or appointments. Scholars have highlighted how organizations can unknowingly retraumatize individuals with trauma histories through day-to-day practices, particularly within marginalized populations that are less likely to be properly assessed or screened and offered adequate supports (Butler, Critelli, & Rinfrette, 2011). As a result, disabled women are likely to simply avoid doctors, diagnostic testing procedures, and other supportive persons, as demonstrated in the current findings. Potentially helpful relationships frequently become a source of distrust and threat for those with trauma histories (Brown, 2010). The reframing of medical procedures and treatment as trauma or series of complex traumas both legitimizes the harm expressed by participants and provides a useful framework for future clinical interventions or supports. Personal experiences of trauma by medical procedures and professionals are routinely discounted due to beliefs that healthcare professionals are helping and pain can be a necessary component to that experience.

Trauma-informed care (TIC) was developed in the mid-1990s in response to calls for service systems to ameliorate, rather than exacerbate, the pervasive biopsychosocial impacts of

trauma and subsequent retraumatization (Brown, 2010; Harris & Follet, 2001). Although there is no scholarly material to date on the use of TIC for disabled women, scholars have highlighted its potential for disabled persons and in training caregiving staff and medical professionals who work with them in particular (Keesler, 2014). The focus of TIC is the promotion of personal safety, autonomy, collaboration and empowerment through staff education and implementation of supportive and empowering treatment options as well as reduction in the use of methods such as forcible restraint (Hodgdon, Kinniburg, Gabowitz, Blaustein, & Spinazzola, 2013). The TIC model and its emphasis on autonomy and choice could be particularly empowering for disabled women who described in the current study frequently feeling powerless in interactions with caregivers, medical professionals, etc. Studies have supported the use of TIC through client reported reduction in symptoms, improved health, lower reported health issues, and improved mental health and substance abuse outcomes (Greenwald et al., 2012; Hodgdon et al., 2013; Morrissey et al., 2005; Weissbecker & Clark, 2007). Understanding physically disabled women as traumatized by medical mistreatment and invasive procedures could help in providing appropriate care as well as beginning to support healing and encourage trust between patient and professional. Within the general trauma literature, safe and predictable relationships, often afforded through caregivers and therapists, can facilitate the sense of security, self-regulation skills and validation necessary to overcome the negative impacts of trauma (Brown, 2010). Further, through a TIC model, healthcare professionals and caregivers can facilitate basic needs for safety and the facilitation of coping skills with minimal training and support (Bath, 2008).

Lastly, Olkin's disability-affirmative therapy model (2001) may provide some helpful considerations and suggestions for therapists unfamiliar with disability and the social model of

disablement. Olkin, who identifies as disabled herself, attempts to bridge the gap between well-intentioned therapists trained in a model of therapy that frames disability as a personal tragedy and clients with disabilities who have had past instances of medical trauma and feeling misunderstood by psychotherapists. She provides basic information regarding different models of disability outside of the medical model most professionals are exposed to during their training, allowing the therapist to meet the client where they are at in terms of understanding disability (Roosen, 2009). Further, there is an emphasis on self-reflection surrounding biases towards disability that will facilitate an affirming view of disability while simultaneously remaining open to exploring the client's view of their own disability. Given the limited literature and training in disability for therapists and findings in the current study, it is recommended that disability-affirmative training be integrated into curricula in addition to other models that emphasize client-centered and anti-oppressive practices.

Limitations

While the current set of studies examined an important and often under researched topic for those living with physical disabilities, there are several limitations to consider. First of all, there are some considerations with regards to the research design. Study 1 was cross-sectional in nature. As a result, the direction of the relationships cannot be determined. For instance, it's highly plausible that disordered eating behaviours could contribute to greater body dissatisfaction, as opposed to the other way around. Longitudinal analyses could be useful in supporting the proposed directions of findings in Study 1. Further, the study relied solely on self-report data. Ideally, the presence of clinical eating disorders should be confirmed through diagnostic interviewing. Also, incorporation of observer data, such as family members or healthcare professionals may have produced different results than what was perceived or

reported by participants with a physical disability. The current study consisted solely of women or trans-identified women. While the study design was purposeful in that the rates of disordered eating are higher in women, nonetheless, a limitation of this dissertation is that the results cannot be generalized to men or male-identified individuals. The qualitative sample was drawn from the quantitative sample. As a result, completing the survey first may have influenced the women's participation in the qualitative interview. Further, this design may have impacted the specific line of questioning that occurred during the qualitative component.

Secondly, the recruitment methods likely impacted the findings. The women with disabilities were recruited mostly through internet-based community groups as well as other local disability groups (e.g., specialized health services, university advocacy groups). The sample may have differed from the general sample of persons with disabilities. For one, these women may have been more engaged in seeking support and community, which could have positively impacted their health and/or well-being. As an example, the women may have taken more of an active management approach to their health and mental health. Next, many of the women in both studies were recruited through university and professional settings (i.e., listserves, Facebook groups). As a result, the sample was small and may have been over-represented with women of higher income levels and educational backgrounds in addition to simultaneously under-representing women from different socially marginalized and/or diverse backgrounds (e.g., racialized women, LGBTQ identified women). Relatedly, the control sample, in Study 1, although age matched, were university students who were, due to their own career status, of comparatively lower socioeconomic standing and educational background. Also, due in part to my own identity as a disabled woman living with a neuromuscular disorder, the sample recruited was probably not proportionally representative across disability diagnoses.

For example, in some cases, I had to personally disclose my own medical diagnosis in order to join an online support group and recruit research participants. This means that a substantial proportion of the current sample also had a neuromuscular disorder. Similarly, the sample also likely under-represented those women with more recently acquired physical disabilities or medical disabilities that impact mobility (e.g., chronic illnesses, multiple sclerosis) due to my own identity as a woman with an acquired disability in addition to the fact that many women with episodic or newly acquired disabilities do not identify as disabled or a person with a disability. This limitation would affect any research looking to recruit self-identified individuals with disabilities. Lastly, the samples consisted solely of women ages 18-40. Although this again was purposeful in increasing the likelihood of recruiting younger women who are mostly likely to be struggling with disordered eating, the results cannot be generalized to youth and older women. Further, this also limited the number of women in the current study who were physically disabled due to age-related conditions.

Regarding the measurement of the constructs of interest in Study 1, there are important considerations with regards to reliability and validity that may have impacted the findings. All of the mental health and disordered eating scales used were not validated in samples of persons with physical disabilities. Within the comments section of the survey, many women wrote specific remarks regarding how they felt the scale did or did not represent their experiences and these data were recorded. For instance, some women described how they feared certain foods not because it would make them gain weight, but rather because they had difficulties swallowing and feared choking.

The measurement of physical disability across the studies also presented with numerous challenges. There was no method to confirm physical disability or individual diagnoses with a

self-identified sample. Some women had difficulties rating their health and the level of impairment associated with their disability if it was episodic in nature. Most of the scales measuring functional disability were developed in rehabilitation or hospital settings and are meant to be used to aid healthcare professionals. As a result, in this study, some of the questions had to be modified or removed to adapt the scale to a self-report style for persons living within the community (see Appendix C). This modification probably contributed to the low inter-item reliability for the Rapid Disability Rating Scale. Furthermore, although efforts were made to minimize participant fatigue by selecting shorter scales, there were more missing data on scales as participants went along. Finally, while an adequate number of women were recruited for the research based on an a priori power calculation, it is possible that a larger sample may have allowed for increased ability to detect significant differences.

Another limitation is that women with disabilities were recruited from different countries. Although the diversity in the sample was welcome, there were not enough participants to conduct cross-sectional analyses by country. These differences may be particularly influential with regards to socioeconomic status, educational backgrounds, and employment status. Countries differ in terms of attitudes and laws associated with disability and disability accommodations. For example, in the qualitative component, a participant from Australia was the only woman to report overt hate speech from strangers based on her disability. Access to appropriate healthcare, support services (e.g., personal support workers/attendants, counseling, healthy eating programs), inclusive environments, and mobility devices can all play an important role in the health, mental health, and social participation of individuals with physical disabilities.

Another potential limitation with regards to the qualitative component of the study would be the open-nature of the interview. Although intentional to encourage the emergence of new themes, there were differences across participants in terms of interview focus. For example, some women spoke more about healthy eating, whereas others focused on barriers in seeking support. It is also important to consider more how my lived experiences impacted the interviews and the analysis. Although I engaged in regular memoing and consultation with supervisors, there may be unanticipated impacts to my embodied presence as a researcher. Given that I use a wheelchair, other wheelchair users communicated our shared experience by seeking validation or not fully elaborating on certain topics that were viewed as 'understood' (e.g., the frustration of local specialized transit systems). For non-wheelchair users, I, at times, sensed a hesitance in exploring with interviewees their negative associations with disability. Interestingly, I also noticed that I had some social capital as a disabled woman, where some women only agreed to participate after learning I too was disabled. It seems that for some participants, I likely inspired a deeper level of sharing. At the same time, my disability could have inhibited other participants. No participants expressed concern over my presence and some remarked that they found my status as a disabled woman helped increase their sense of trust and openness. Nevertheless, I needed to constantly engage in reflexivity and remain conscious of how my embodied experiences influenced my study throughout to avoid drawing conclusions grounded in my own experiences rather than within and across the participant's interviews.

Closing Remarks

The current set of studies explored disordered eating and body dissatisfaction in women with physical disabilities. Although overall, disabled women were found to be at equal risk for

developing an eating disorder in comparison to their able-bodied counterparts, the current findings highlighted *how* disabled women experience unique circumstances that impact disordered eating identification, manifestation and treatment. Although it was largely assumed in past research that stress caused by disability contributed to risk for disordered eating, the current study has highlighted the accumulated impact of health problems, negatively ascribed disability meaning, and less time since diagnosis, adding a greater understanding to how physical disability can lead to higher instances of disordered eating. Beyond individual risk factors, the current studies also examined how a broader societal devaluation of disabled and fat bodies can lead to general body dissatisfaction and mental health issues as well as disordered eating and other body modification practices (e.g., dress to impress, compensation). Conversely, in a society that idealizes productivity, beauty and independence, different (read: threatening) bodies, including those with disabilities and those who are overweight, will continuously struggle to exist, let alone succeed and thrive. In addition, both individual and social factors related to disability negatively impacted disabled women's capacities to seek support and treatment for issues related to disordered eating. More research is needed that can explore the question of treatment effectiveness for disabled women struggling with disordered eating. Broader social changes are needed to address health inequities in general for disabled women that contribute to the problem of disordered eating treatment.

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Tables and Figures

Legend

BAI = Beck Anxiety Inventory

BDI = Beck Depression Inventory

RSES = Rosenberg Self-Esteem Scale

BES = Body Esteem Scale

EAT = Eating Attitudes Test

AI = Appearance Schemas Inventory

RDRS = Rapid Disability Rating Scale

RES = Revised Restraint Scale

GBES = Gormally Binge Eating Scale

EDEQ = Eating Disorder Examination Questionnaire

DisRat = Subjective Disability Rating (out of 5)

HealthR = Subjective Health Ranking (out of 10)

BMI = Body Mass Index (kg/m^2)

ADL = Activities of Daily Living (e.g., showering)

Tables

Table 1

Pearson correlational matrix for dependent measures in Study 1

	BAI	BDI	RSES	BES	EAT	AI	PDSES	RSRS	RES	GBES	EDEQ	DisRat	HealthR
BAI	1												
BDI	.67**	1											
RSES	-.49**	-.73**	1										
BES	-.45**	-.56**	.67**	1									
EAT	.36**	.52**	-.43**	-.41**	1								
AI	.27**	.34**	-.30**	-.30**	.55**	1							
PDSES	-.16	-.38**	.37**	.46**	-.14	-.21*	1						
RDRS	.002	.10	-.02	-.15	.09	.04	-.33**	1					
RES	.36**	.45**	-.44**	-.43**	.68**	.06	.001	-.02	1				
GBES	.47**	.61**	-.53	-.50**	.68**	.53**	-.17	-.003	.72**	1			
EDEQ	.41**	.54**	-.55**	-.57**	.75**	.46**	-.21*	-.01	.79**	.78**	1		
DisRat	.27**	.33**	-.44**	-.39**	.15	.14	-.52**	.38**	.11	.20*	.23*	1	
HealthR	-.46**	-.42**	.39**	.36**	-.01	-.01	.07	-.03	-.27**	-.30**	-.28**	-.31**	1

* indicates significance level $p < .05$

** indicates significance level $p < .001$

Table 2

One-way ANOVA comparing women with and without disabilities across measures of body esteem and disordered eating

Measure	**Control group** ***M(S.D.)***	**Disabled women** ***M(S.D.)***	***F (df1, df2)***	***p***
BES	114.50(25.08)	101.15(21.37)	17.78 (1, 215)	<.001**
RRS	14.23(6.75)	13.61(6.87)	0.47 (1, 227)	0.493
GBES	10.43(10.67)	9.74(9.29)	0.24 (1, 205)	0.623
EDEQ	2.05(1.55)	2.04(1.45)	0,003 (1, 222)	0.958

*$p < .05$
**$p < .001$

Table 3

One-way ANOVA comparing women with and without disabilities across measures of mental health

Measure	**Control group *M* *(S.D.)***	**Disabled women *M* *(S.D.)***	***F (df1, df2)***	***p***
BAI	12.96(12.62)	16.44(11.26)	4.48 (1, 211)	0.03*
BDI	14.03(11.55)	15.20(12.15)	0.53 (1, 215)	0.47
RSES	19.48(6.19)	19.00(6.56)	0.32 (1, 227)	0.57

*$p < .05$
**$p < .001$

Table 4.

Hypothesis 2: Multiple regression predictors - Subjective disability, objective disability and health rank on dependent measures of disordered eating, body esteem and mental health

Dependent Variable (a)	***F* (df_1, df_2)**	***p***	**% Variance Explained (Adjusted R^2)**
Dietary Restraint	3.16 (3, 110)	.03*	5.40%
EDE-Q	3.00 (3, 110)	.03*	5.00%
Binge Eating	1.88 (3, 110)	.14	2.30%
Depression	5.93 (3, 110)	.001*	11.60%
Anxiety	6.61 (3, 110)	<.001**	13.0%
Self-Esteem	19.87 (3, 110)	<.001**	33.40%
Body Esteem	7.12 (3, 98)	<.001**	17.90%

Dependent Variable (b)	**Predictor Variable**	**ΔR^2**	***B***	***SE***	**β**	***t***	***p***
Dietary Restraint – RRS	Subjective Disability	.079	.09	.13	.08	.71	.48
	Objective Disability (RDRS)		-.22	.30	-.08	-.75	.45
	Health Rank		-.78	.29	-.26	-2.65	.01*
Disordered Eating - EDE-Q	Subjective Disability	.076	.04	.02	.17	1.63	.11
	Objective Disability		-.04	.06	-.08	-.78	.44
	Health Rank		-.11	.06	-.19	-1.96	.05*
Binge Eating – GBES	Subjective Disability	.049	.14	.16	.10	.89	.37
	Objective Disability		-.13	.39	-.04	-.35	.73
	Health Rank		-.67	.36	-.18	-1.85	.07
Depression – BDI	Subjective Disability	.139	.50	.23	.22	2.19	.03*
	Objective Disability		-.31	.53	-.06	-.58	.56
	Health Rank		-1.47	.52	-.26	-2.80	.01*
Anxiety – BAI	Subjective Disability	.153	.14	.18	.08	.76	.45
	Objective Disability		-.07	.41	-.02	-.17	.87
	Health Rank		-1.64	.41	-.36	-3.98	<.001**
Self-Esteem – RSES	Subjective Disability	.351	-.53	.10	-.45	-5.15	<.001**
	Objective Disability		.59	.24	.20	2.43	.02*
	Health Rank		.97	.24	.33	4.05	.001**
Body Esteem – BES	Subjective Disability	.179	-1.23	.40	-.33	-3.11	.002**
	Objective Disability		-.21	.86	-.02	-.24	.81
	Health Rank		1.70	.93	.18	1.81	.07

*$p < .05$
**$p < .001$

Table 5

Hypothesis 2: One-way ANOVA examining differences between congenital and acquired disabilities across measures of disordered eating, body esteem and mental health.

Measure	**Congenital Disability Group *M(S.D.)* (n=89)**	**Acquired Disability Group *M(S.D.)* (n=28)**	***F (df1, df2)***	***p***
Health Rank	7.52(1.71)	4.67(2.29)	48.84 (1, 113)	<0.001**
Disability Rank	17.69(5.62)	17.35(5.77)	0.08 (1, 115)	0.78
BAI	15.08(10.50)	20.50(12.66)	4.67 (1, 102)	0.03*
BDI	14.91(12.37)	16.09(11.62)	0.19 (1, 105)	0.67
RSES	19.38(6.52)	17.82(6.68)	1.20 (1, 115)	0.28
BES	101.14(20.96)	101.18(23.03)	0.00 (1, 105)	0.99
RDRS	12.25(2.45)	11.04(2.36)	4.84 (1, 101)	0.03*
RRS	13.24(6.31)	14.78(8.44)	1.08 (1, 115)	0.30
EDEQ	2.00(1.42)	2.16(1.54)	0.24 (1, 110)	0.62
GBES	9.14(8.70)	11.50(10.83)	1.21 (1, 96)	0.28

*$p < .05$
**$p < .001$

Table 6

Hypothesis 2: Regression predictor – Length of time (years) disabled on dependent measures of disordered eating, body esteem and mental health

Dependent Variable (a)	***F* (df_1, df_2)**	***p***	**% Variance Explained (Adjusted R^2)**
Dietary Restraint (RRS)	0.49 (1, 110)	0.487	0
Disordered Eating (EDE-Q)	0.02 (1, 105)	0.885	0
Binge Eating (GBES)	2.33 (1, 92)	0.130	1.4%
Depression (BDI)	9.33 (1, 100)	0.003**	7.6%
Anxiety (BAI)	14.79 (1, 97)	<0.001**	12.3%
Self-Esteem (RSES)	7.29 (1, 110)	0.008**	5.4%
Body Esteem (BES)	0.22 (1, 100)	0.638	0.2%
Objective Disability (RDRS)	0.15 (1, 96)	0.698	0
Disability Rating	0.77 (1, 110)	0.383	0
Health Ranking	13.06 (1, 108)	<0.001**	10%

Dependent Variable (b)	**ΔR^2**	***B***	***SE***	**β**	***t***	***p***
Anxiety (BAI)	.13	-.43	.11	-.36	-3.85	<0.001**
Depression (BDI)	.09	-.37	.12	-.29	-3.05	0.003**
Self-Esteem (RSES)	.06	.17	.06	.25	2.70	0.008**
Body Esteem (BES)	.002	.11	.22	.05	.47	0.638
Obj. Disability (RDRS)	.002	.01	.03	.04	.39	0.698
Dietary Restraint (RRS)	.004	-.05	.07	-.07	-.70	0.487
Binge Eating (GBES)	.03	-.15	.10	-.16	-1.53	0.130
Disordered Eating (EDEQ)	0	-.002	.02	-.01	-.15	0.885
Disability Rating	.01	.05	.06	.08	.88	0.383
Health Ranking	.11	.08	.02	.33	3.61	<0.001**

*$p < .05$
**$p < .001$

Table 7

Hypothesis 3: Regression predictor – Body Esteem as measured by BES on dependent measures of disordered eating and mental health

Dependent Variable (a)	***F* (df_1, df_2)**	***p***	**% Variance Explained (Adjusted R^2)**
Dietary Restraint (RRS)	13.27 (1, 105)	<0.001**	10.4%
Disordered Eating (EDE-Q)	31.43 (1, 105)	<0.001**	22.3%
Binge Eating (GBES)	18.63 (1, 95)	<0.001**	15.5%
Depression (BDI)	49.73 (1, 104)	<0.001**	31.7%
Anxiety (BAI)	21.81 (1, 101)	<0.001**	16.9%
Self-Esteem (RSES)	93.51 (1, 105)	<0.001**	46.6%

Dependent Variable (b)	ΔR^2	***B***	***SE***	**B**	***t***	***p***
Anxiety (BAI)	.18	-.22	.05	-.42	-4.67	<0.001**
Depression (BDI)	.32	-.32	.05	-.57	-7.05	<0.001**
Self-Esteem (RSES)	.47	.21	.02	.69	9.67	<0.001**
Dietary Restraint (RRS)	.11	-.11	.03	-.34	-3.64	<0.001**
Binge Eating (GBES)	.16	-.18	.04	-.41	-4.32	<0.001**
Disordered Eating (EDEQ)	.22	-.03	.01	-.48	-5.61	<0.001**

*$p < .05$
**$p < .001$

Table 8

Summary of quantitative results for 11 interview participants (Study 2)

Name	**BMI**	**RES**	**EAT**	**EDEQ**	**GBES**	**RSES**	**BDI**	**BAI**	**BES**	**AI**	**RDRS**	**Disability Rating out of 30**	**Health Rank out of 10**
Total Mean (Standard Deviation)	24.22 (9.03)	13.61 (6.87)	11.81 (10.59)	2.04 (1.45)	9.74 (9.29)	19.00 (6.56)	15.20 (12.15)	16.44 (11.26)	101.15 (21.37)	69.58 (14.07)	11.96 (2.47)	17.62 (5.63)	6.82 (2.22)
Kendra	28.17	25*	19	4.68*	16	15	22	40**	57**	94*	11	26*	6
Michelle	17.84	25*	31*	4.82*	31**	16	15	28*	93	71	15*	14	8
Carrie	26.50	17	6	3.52*	20*	14	14	15	99	86*	12	25*	6
Amy	-	16	9	2.22	22*	21	14	29*	108	66	13	22	7
Jess	33.49*	32**	39**	5.91**	44**	3**	38*	27	77*	87*	9	21	1**
Heather	20.09	28**	39**	3.74*	28*	16	33*	32*	107	96*	8*	11*	9
Emily	24.17	11	25*	2.96	13	14	8	8	83	72	10	27*	4*
Jennifer	17.79	21*	26*	4.30*	22*	19	20	18	101	95*	16*	23	7
Mariam	20.49	19	31*	4.65*	13	10*	21	19	88	93*	12	23	9
Hannah	35.36*	19	12	3.74*	7	8*	19	20	58*	61	9	21	6
Kelly	23.93	24*	42**	3.16	10	11*	23	18	69*	94*	15*	10*	10*

* 1 standard deviation away from mean
** 2 standard deviations away from the mean

Figures

Figure 1

Level of assistance reported by women with disabilities from 0 (no assistance required/completely independent) to 5 (full assistance required) (n = 114)

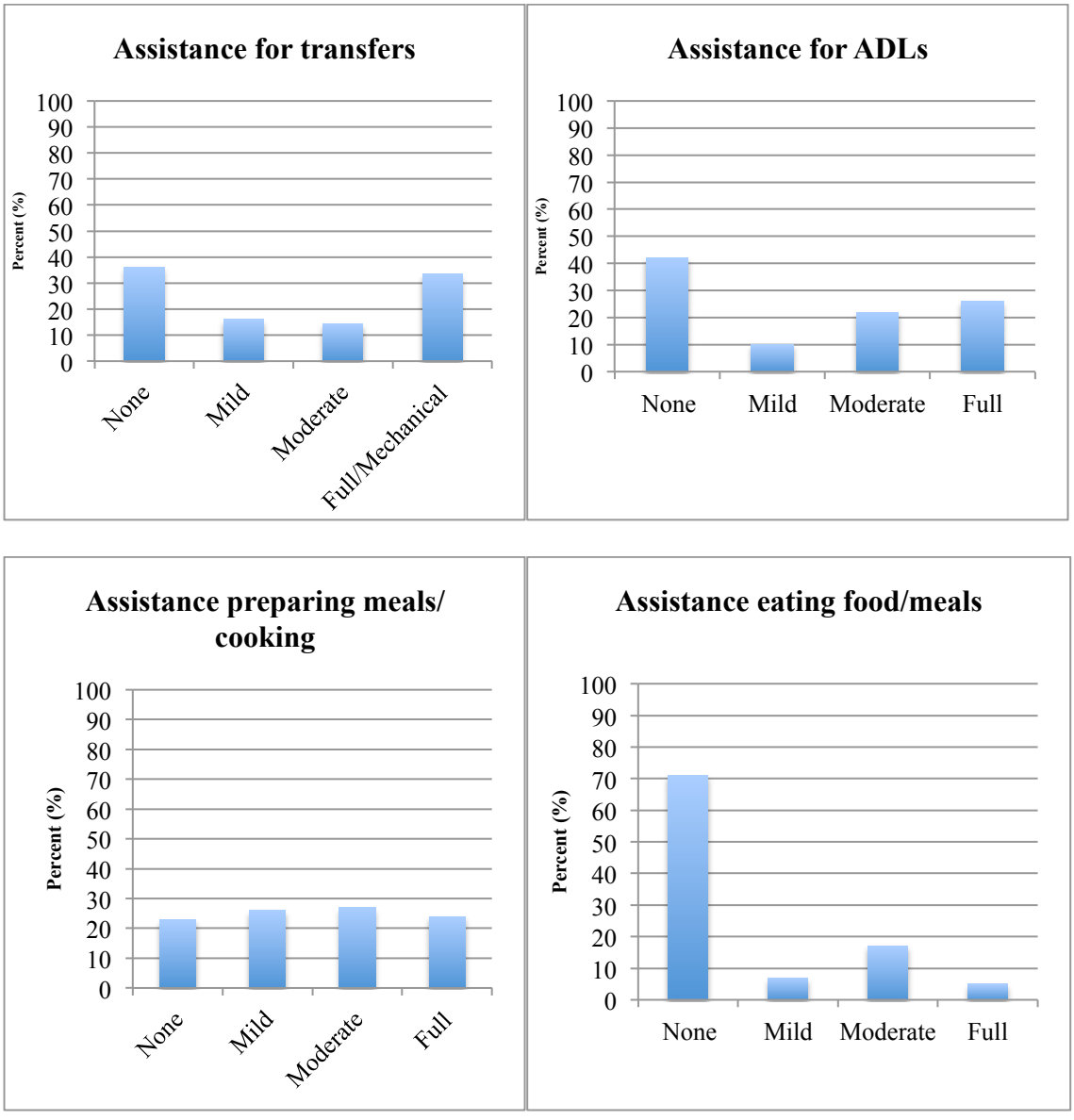
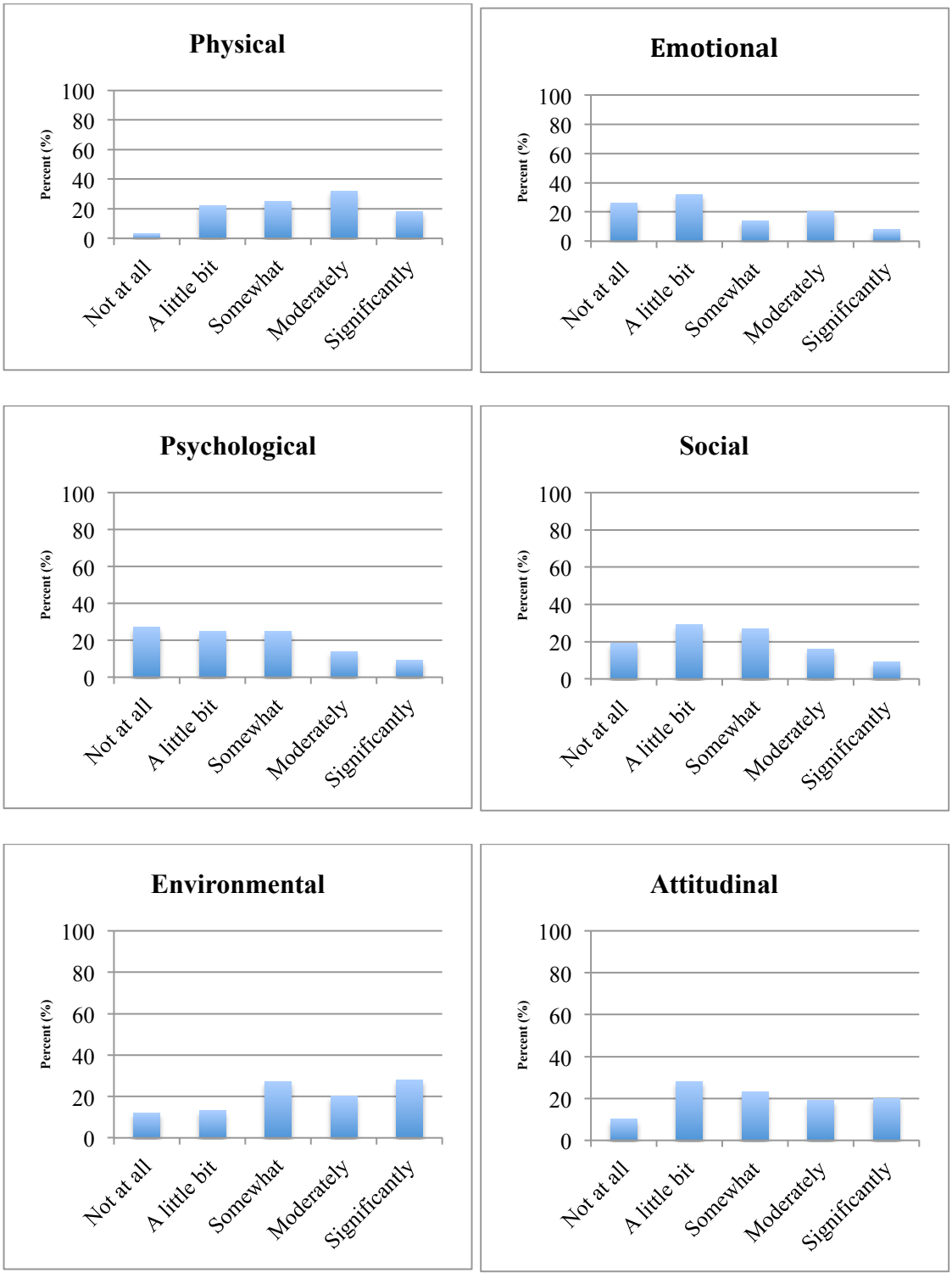


Figure 2

Subjective Disability Rating across participants with disabilities from 0 (not at all disabled) to 5 (completely disabled) (n = 114)



Appendix A

Recruitment Message

Email/Message recruiting participants for Study 1

Hi Everyone!

My name is Kaley Roosen and I am a PhD student at York University's Clinical Psychology program. As part of my dissertation research, I am looking at women with physical disabilities and their attitudes and behaviours related to eating, body image, dieting, and disability. Research in this area is almost nonexistent. I am hoping that this research will add to the knowledge of current programs and resources for women with physical disabilities, as well as inform some current medical practices, which may or may not be based on factual information and are heavily influenced by assumptions.

The study is 2 parts. Part 1 is an online survey. Please consider filling it out. It will take approximately 30-45 minutes of your time. Not only will you be adding to this important area of research, but your name will also be put into a draw to win an I-Pad 2!

Also, if you are interested in this area of research, there may be an opportunity to participate in Part 2 of the study, in which I will be conducting one-on-one interviews where you can discuss openly your experiences in this area.

To be eligible, you must identify as:
1) A Woman who has a Physical Disability or Significant Mobility Impairment &
2) Aged between 16-40 years old.

Here is the study link: https://www.surveymonkey.com/s/JZD2M2G

Thank-you for your time and please feel free to contact me if you have questions/comments/concerns.

Appendix B

Study 1 Informed Consent

INFORMED CONSENT

The following is a consent form, which is designed to provide you with information about the nature and purpose of this study. Please read through the form and make sure that you understand and agree with everything before continuing on with the study.

Study Name: "Eating, Body Image & Disability"

Purpose of the Research: The investigation will examine how individual differences in several interpersonal variables and differences in individual abilities relate to attitudes and behaviours related to eating and body image.

What You Will be Asked to Do: This study involves filling out a questionnaire package. The questionnaires will ask about your experiences with food and your feelings/thoughts about your body and eating. The questionnaires should take approximately 30 minutes to complete.

Benefits: The potential findings are of empirical, theoretical, and practical significance for cognitive, health, and clinical psychology.

By agreeing to participate in this study, you will receive the benefit of a greater understanding of self and the psychology research process. Additionally, your name will be entering into a draw to win an I-Pad 2. If you are a York University student who signed up through the URPP system, you will receive 1.0 credit towards your first year psychology course.

Risks: We do not foresee any risks from your participation in the research. However, if you experience any discomfort by participating in this study, we will provide you with referrals in which you can access support services and resources. This information can be provided by contacting the principal investigators; Kaley Roosen, M.A. or Jennifer Mills, Ph.D. C. Psych as well as it will be provided to you at the end of the study.

Voluntary Participation: Your participation in the study is completely voluntary and you may choose to stop participating at any time. Your decision not to volunteer will not influence the nature of your relationship with York University either now, or in the future.

Withdrawal from the Study: You can stop participating in the study at any time, for any reason, if you so decide. Your decision to stop participating, or to refuse to answer particular questions, will not affect your relationship with the researchers or York University. In the event you withdraw from the study, all associated data collected will be immediately destroyed wherever possible.

Confidentiality: All information you supply during the research will be held in confidence and your name will not appear in any report or publication of the research. Your data will be safely stored in a locked facility and only research staff will have access to this information. The data will be stored for 10 years time, after which it will

be destroyed. Confidentiality will be provided to the fullest extent possible by law.

Questions About the Research: If you have questions about the research in general or about your role in the study, please feel free to contact Dr. Jennifer Mills either by telephone or by e-mail or Kaley Roosen by email. This research has been reviewed and approved by the Human Participants Review Sub-Committee, York University's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines.

Researchers:
Principal Investigator: Kaley Roosen M.A.
Ph.D. Candidate Clinical Psychology, York University

Jennifer Mills, Ph.D., C. Psych.
Associate Professor, Department of Psychology, York University

By clicking the "YES" option below, I consent to participate in the study "Eating, Body Image & Disability" conducted by Kaley Roosen and Dr. Jennifer Mills. I have understood the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form. By clicking the "YES" option below, I am indicating my consent.

YES NO

Informed Consent Study 2

INFORMED CONSENT
Title: "Follow-Up: Eating, Body Image & Disability

Investigators: Jennifer Mills, Ph.D. C.Psych., York University
Kaley Roosen, MA Clinical Psychology, York University

The proposed investigation will examine the experience of eating, dieting and body image for women with physical disabilities. If you decide to participate in this study you will be asked to participate in a one-on-one interview with a female researcher. During the interview, you will be asked questions about your experiences with eating, dieting, body image and accessibility/disability. In addition to addressing specific topics, you will have the opportunity to elaborate on your thoughts, feelings, and/or concerns related to your experience. You may choose to skip (i.e., not answer) questions you find uncomfortable and/or discontinue participation at any time during the interview.

You will also be asked for some demographic information (e.g., age, education) about you and the impact your disability(s) have on your life.

This interview will either be conducted in-person or over the telephone. In either case, the interview will be audio-recorded and last for approximately 1 hour. In-person interviews will take place either at York University or at the participant's home.

The audio recordings will be transcribed and the transcripts will be analyzed to determine common themes across all participants. You will not be identified by name on the transcripts nor on any other documents kept on file linking your name to specific statements. Your participation will be kept strictly confidential. However, it is possible that word-for-word excerpts from this interview may be used in presentations and reports, and that your words may be quoted verbatim. Were this to occur, your identity would be concealed and protected. However, it is possible that you (or people who know you well) might recognize words-in-print or spoken in a presentation as belonging to you.

All information you supply during the research will be held in confidence and your name will not appear in any report or publication of the research. Your data will be safely stored in a locked facility and only research staff will have access to this information. The data will be stored for 10 years time, after which it will be destroyed. Confidentiality will be provided to the fullest extent possible by law.

The potential findings are of empirical, theoretical, and practical significance for cognitive, health, and clinical psychology. We do not foresee any risks from your participation in the research. However, if you experience any discomfort by participating in this study, we will provide you with referrals in which you can access support services and resources. This information can be provided by contacting the principal investigators; Kaley Roosen, M.A., or Jennifer Mills, Ph.D. C. Psych, as well as, it will be provided to you at the end of the study.

By agreeing to participate in this study, you will receive the benefit of a greater understanding of self and the psychology research process. Additionally, your name will be entering into a draw to win a gift certificate for Chapter's/Indigo Book Stores.

Your participation in the study is completely voluntary and you may choose to stop participating at any time, for any reason without penalty. Your decision not to volunteer or to refuse to answer particular questions will not influence your treatment during the study or nature of your relationship with the researchers, York University or any other group associated with the project either now, or in the future. In the event you withdraw from the study, all associated data collected will be immediately destroyed.

If you have questions about the research in general or about your role in the study, please feel free to contact Dr. Jennifer Mills either by telephone or by e-mail or Kaley Roosen by email. This research has been reviewed and approved by the Human Participants Review Sub-Committee, York University's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines.

Legal Rights and Signatures:
I _____ consent to participate in "Follow-up: Eating, Body Image and Ability" conducted by Kaley Roosen and Dr. Jennifer Mills. I have understood the nature of this project and wish to participant. I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

Signature _____ **Date** _____
Participant

Signature _____ **Date** _____
Witness

Principal Investigators:
Jennifer Mills, Ph.D., C. Psych.
Department of Psychology, York University

Kaley Roosen M.A. Clinical Psychology
Department of Psychology, York University

Appendix C

Measures

Demographics

1. Sex: □ Male □ Female □ Transgender

2. Date of Birth: _____
dd/mm/yyyy

3. Current age: _____

4. Height: _____

5. Weight: _____

6. Ethnic Background (check as many as apply to you):

1. □ African-Caribbean
2. □ African-Canadian
3. □ South Asian (e.g., India, Pakistan, Sri Lanka)
4. □ East Asian (e.g., Hong Kong, China, Vietnam, Korea)
5. □ Middle Eastern or North African (e.g., Iran, Israel, Egypt, Morocco)
6. □ White
7. □ Hispanic / Latino/a
8. □ Aboriginal
9. □ Other (please specify) _____

_____

In the above question, a list of ethnic backgrounds was provided. However, this list may or may not specify how you identify. Regardless of your answer to the previous question, how do you identify your ethnic background (s)?

Ethnically, I identify as:

_____

7. Highest Level of Education Achieved:

1. □ Less than Grade 12
2. □ Grade 12
3. □ Some College/University
4. □ College/University Degree
5. □ Post-Graduate Degree (Masters, Teachers College, etc.)

8. Current Marital Status:

1. □ Single
2. □ In a relationship
3. □ Currently Married
4. □ Separated/Divorced

5. □ Widowed
6. □ Cohabiting

10.Where do you live?

1. □ University Campus/Residence
2. □ Independent in Community
3. □ Assisted Living (Supportive Housing, Outreach attendant Services)
4. □ Hospitalized
5. □ With Parents/Guardians in a Private Residence

11.Main work/employment status

1. □ Paid Work
2. □ Self-employed
3. □ Non-paid work (volunteer, charity)
4. □ Student
5. □ Keeping house/Homemaker
6. □ Retired
7. □ Unemployed (health reasons)
8. □ Unemployed (other reasons)
9. □ Other *specify*:
   _____

12.Please rate your overall health in the past thirty days where 1 = Poor Health and 10 = Excellent Health:

1 2 3 4 5 6 7 8 9 10

13. Do you currently have a physical disability or significant mobility impairment?

□ Yes □ No

14. What type of disability/diagnosis do you have (e.g., Spinal Cord Injury, Neuromuscular Disorder, Cerebral Palsy, Spina Bifida, etc.)?

_____

15) Please select any mobility aids which you use on a regular basis (Please select all applicable)?

a. manual wheelchair
b. electric wheelchair
c. motorized scooter
d. walker
e. cane
f. other: _____
g. I do not use any mobility aids

16) Please indicate the level of assistance you require for transfers (i.e., moving from one chair to another chair or to bed)
a. no assistance required
b. some mild assistance required (i.e., I require the use of grab bars)
c. some moderate assistance required (i.e., I require assistance from another person to stand and pivot)
d. full assistance required (i.e., I require a full life from another person)
e. full assistance required / use of mechanical lift (i.e., hoyer lift, ceiling track lift).

17) How much assistance to you require for activities of daily living or to complete your daily routine (i.e., getting ready in the morning, dressing, toileting, etc.)?
a. no assistance required
b. some mild assistance required
c. some moderate assistance required (I sometimes need attendant services or help from my family but can perform some tasks independently)
d. full assistance required (I use attendant services or my family helps me for the majority of activities)

18) How much assistance to you require for grocery shopping, preparing meals and/or cooking?
a. No assistance required
b. Some mild assistance required
c. Some moderate assistance required (I sometimes need attendant services or help from my family but can perform some tasks independently)
d. Full assistance required (I use attendant services or my family helps me for the majority of activities)

19) How much assistance to you require for eating meals?
a. No assistance required
b. Some mild assistance required
c. Some moderate assistance required (I sometimes need attendant services or help from my family but can perform some tasks independently)
d. Full assistance required (I use attendant services or my family helps me for the majority of activities)

20) Overall, how severe do you feel your disability is:

☐ Mild ☐ Moderate ☐ Severe ☐ N/A

21) Number of years living with your disability: _____

22) Have you had your disability since birth:

☐ Yes ☐ No ☐ N/A

23) To what extent do you feel your disability impacts your physical appearance?

□ Not at all □ Mildly □ Moderately □ Significantly □ N/A

24) How disabled do you feel physically? Are the actions you take or wish to take limited by physical restrictions?

□ Not at all □ A little Bit □ Somewhat □ Moderately □ Significantly □ N/A

25) How disabled do you feel emotionally? Does your disability affect your mood, temperament and/or disposition?

□ Not at all □ A little Bit □ Somewhat □ Moderately □ Significantly □ N/A

26) How disabled do you feel psychologically? Does your disability affect your thoughts and/or feelings?

□ Not at all □ A little Bit □ Somewhat □ Moderately □ Significantly □ N/A

27) How disabled do you feel socially? Does your disability affect interactions with family, friends and within school and/or community settings?

□ Not at all □ A little Bit □ Somewhat □ Moderately □ Significantly □ N/A

28) How disabled do you feel environmentally? Does your disability affect your access to resources, community settings, transportation and education/employment?

□ Not at all □ A little Bit □ Somewhat □ Moderately □ Significantly □ N/A

29) How disabled do you feel attitudinally? Does your disability impact the way other people treat you or view you?

□ Not at all □ A little Bit □ Somewhat □ Moderately □ Significantly □ N/A

Rapid Disability Rating Scale (Linn, 1976): Original

Directions: Please rate the following items

Activity	Ability	Points
Eating	No assistance	1
	Moderate Assistance	2
	Considerable Assistance	3
Diet	Regular diet	1
(as prescribed by medical professional)	Modified regular diet	2
	Special diet	3
Medications	Rarely	1
	Occasionally	2
	Every day	3
Speech	Not impaired	1
	Moderately impaired	2
	Unable to be understood by others	3
Hearing	No problems	1
	Moderately impaired	2
	Deaf/Unable to hear	3
Sight	No problems (with or without glasses)	1
	Moderately impaired	2
	Blind/Unable to see	3
Walking	No assistance	1
	Need help of another person or use of crutch/walker	2
	Unable to walk	3
Bathing	No assistance	1
	Moderate assistance	2
	Considerable assistance	3
Dressing	No assistance	1
	Moderate assistance	2

	Considerable assistance	3
Incontinence	Never	1
	Occasionally	2
	All of the time	3
Shaving	No assistance	1
	Moderate assistance	2
	Considerable assistance	3
Safety supervision	Never	1
	Sometimes	2
	All of the time	3
Confined to bed	Not at all	1
	Part of the day	2
	All the time	3
Mentally confused	Never	1
	Occasionally	2
	All of the time	3
Uncooperative	Never	1
	Occasionally	2
	All of the time	3
Depression	Never	1
	Occasionally	2
	All of the time	3

Rapid Disability Rating Scale: Revised for Study 1

Directions: Please rate the following items

Activity	Ability	Points
Eating	No assistance	1
	Moderate Assistance	2
	Considerable Assistance	3
Diet	Regular diet	1
(as prescribed by medical professional)	Modified regular diet	2
	Special diet	3
Medications	Rarely	1
	Occasionally	2
	Every day	3
Speech	Not impaired	1
	Moderately impaired	2
	Unable to be understood by others	3
Hearing	No problems	1
	Moderately impaired	2
	Deaf/Unable to hear	3
Sight	No problems (with or without glasses)	1
	Moderately impaired	2
	Blind/Unable to see	3
Walking	No assistance	1
	Need help of another person or use of crutch/walker	2
	Unable to walk	3
Dressing	No assistance	1
	Moderate assistance	2
	Considerable assistance	3

Eating History

115. Have you ever been advised by a Health Care Provider that you needed to lose weight?

Yes

No

116. If you answered YES, please specify who advised you (your doctor? a dietician? other?)

_____

117. If you answered YES: WHEN (year) was the last time your health care provider(s) suggested that you needed to lose weight and HOW MANY TIMES (once, a few times, more than 5 times, all your life) has a health care provider recommended that you lose weight in your lifetime?

_____

118. If you answered YES: How much weight (in lbs) approximately did your health care provider(s) recommend you lose?

_____

119. Have you ever been advised by anyone else that you needed to lose weight (i.e., family member, friend, attendant)? Please specify below.

_____

120. Do YOU feel that you currently need to lose weight? Please specify below.

Yes

No

121. If you answered YES: How much weight (in lbs) do you feel you need to lose?

_____

122. If you answered YES: Why do you feel you currently need to lose weight? (Health? Appearance? Other - Please describe)

_____

123. If Applicable, Please Describe: How does your disability medically impact your eating, weight or nutrition (For example, difficulty swallowing, medications that make you lose/gain weight or affect your appetite, unable to chew foods, etc.)

_____

124. Have you ever been diagnosed with an Eating Disorder? If yes, please indicate the type of Eating Disorder (Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder, Other) and time of diagnosis (year).

_____

125. Any additional comments?

_____

Restraint Scale-Revised (Polivy, Herman & Howard, 1988)

Please answer the following items by selecting the alternatives below the question. Do not include weight changes due to pregnancy or physical illness.

43. How often are you dieting?
Never
Rarely
Sometimes
Often
Always

44. What is the maximum amount of weight (in pounds) that you have ever lost in one month?
0-4lbs
5-9lbs
6-14lbs
15-19lbs
over 20lbs

45. What is your maximum weight gain within a week?
0-1lbs
1.1-2lbs
2.1-3lbs
3.1-5lbs
over 5.1lbs

46. In a typical week how much does your weight fluctuate?
0-1lbs
1.1-2lbs
2.1-3lbs
3.1-5lbs
over 5.1lbs

47. Would a weight fluctuation of 5 pounds affect the way you live your life?
Not at all
Slightly
Moderately
Very much

48. Do you eat sensibly in front of others and splurge alone?
Never
Rarely
Often
Always

49. Do you give too much time and thought to food?
Never
Rarely
Often
Always

50. Do you have feelings of guilt after overeating?
Never
Rarely
Often
Always

51. How conscious are you of what you are eating?
Not at all
Slightly
Moderately
Extremely

52. How many pounds over your desired weight were you at your maximum weight?
0-1lbs
1-5lbs
6-10lbs
11-20lbs
over 21lbs

53. Any additional comments?

Eating Disorder Examination Questionnaire (EDE-Q: Fairburn & Cooper, 1993)

Eating Questionnaire
The following questions are concerned with the PAST FOUR WEEKS ONLY (28 days). Please read each question carefully and choose the appropriate response. Please answer ALL the questions.

ON HOW MANY DAYS OUT OF THE PAST 28 DAYS...

176. Have you been deliberately TRYING to limit the amount of food you eat to influence your weight or shape?
No days
1-5 days
6-12 days
13-15 days
16-22 days
23-27 days
Every day

177. Have you gone for long periods of time (8 hours or more) without eating anything in order to influence your shape or weight?
No days
1-5 days
6-12 days
13-15 days
16-22 days
23-27 days
Every day

178. Have you TRIED to avoid eating foods which you like in order to influence your shape or weight?
No days
1-5 days
6-12 days
13-15 days
16-22 days
23-27 days
Every day

179. Have you TRIED to follow definite rules regarding your eating in order to influence your shape or weight; for example, a calorie limit, a set amount of food, or rules about what or when you should eat?
No days
1-5 days
6-12 days
13-15 days

16-22 days
23-27 days
Every day

180. Have you wanted your stomach to be empty?
No days
1-5 days
6-12 days
13-15 days
16-22 days
23-27 days
Every day

181. Has thinking about food or its calorie content made it much more difficult to concentrate on things you are interested in; for example, read, watch TV, or follow a conversation?
No days
1-5 days
6-12 days
13-15 days
16-22 days
23-27 days
Every day

182. Have you been afraid of losing control over eating?
No days
1-5 days
6-12 days
13-15 days
16-22 days
23-27 days
Every day

183. Have you had episodes of binge eating?
No days
1-5 days
6-12 days
13-15 days
16-22 days
23-27 days
Every day

184. Have you eaten in secret? (Do not count binges.)
No days
1-5 days
6-12 days

13-15 days
16-22 days
23-27 days
Every day

185. Have you definitely wanted your stomach to be flat?
No days
1-5 days
6-12 days
13-15 days
16-22 days
23-27 days
Every day

186. Has thinking about shape or weight made it more difficult to concentrate on things you are interested in; for example, read, watch TV, or follow a conversation?
No days
1-5 days
6-12 days
13-15 days
16-22 days
23-27 days
Every day

187. Have you had a definite fear that you might gain weight or become fat?
No days
1-5 days
6-12 days
13-15 days
16-22 days
23-27 days
Every day

188. Have you felt fat?
No days
1-5 days
6-12 days
13-15 days
16-22 days
23-27 days
Every day

189. Have you had a strong desire to lose weight?
No days
1-5 days
6-12 days

13-15 days
16-22 days
23-27 days
Every day

190. OVER THE PAST FOUR WEEKS (28 DAYS)
On what proportion of times that you have eaten have you felt guilty because of the effect on your shape or weight? (Do not count binges.)
None of the times
A few of the times
Less than half the times
Half the times
More than half the times
Most of the time
Every time

191. Over the past four weeks (28 days), have there been any times when you have felt that you have eaten what other people would regard as an unusually large amount of food given the circumstances?
No
Yes

192. How many such episodes have you had over the past four weeks? (Please put the appropriate number in the box provided.)

_____

193. During how many of these episodes of overeating did you have a sense of having lost control over your eating? (Please put the appropriate number in the box provided.)

_____

194. Have you had other episodes of eating in which you have had a sense of having lost control and eaten too much, but have NOT eaten an unusually large amount of food given the circumstances?
No
Yes

195. How many such episodes have you had over the past four weeks? (Please put the appropriate number in the box provided.)

_____

196. Over the past four weeks have you made yourself sick (vomitted) as a means of controlling your weight or shape?
No
Yes

197. How many times have you done this over the past four weeks? (Please put the appropriate number in the box provided.)

_____

198. Have you taken laxatives as a means of controlling your shape or weight?
No
Yes

199. How many times have you done this over the past four weeks? (Please put the appropriate number in the box provided.)

_____

200. Have you taken diuretics (water tablets) as a means of controlling your shape or weight?
No
Yes

201. How many times have you done this is the past four weeks? (Please put the appropriate number in the box provided.)

_____

202. Have you exercised HARD as a means of controlling your shape or weight?
No
Yes

203. How many times have you done this over the past four weeks? (Please put the appropriate number in the box provided.)

_____

204. OVER THE PAST FOUR WEEKS (28 DAYS)...
(Please choose the number which best describes your behaviour)
Has your weight influenced how you think about (judge) yourself as a person?
0- Not at all
1
2- Slightly
3
4- Moderately
5
6- Markedly

205. Has your shape influenced how you think about (judge) yourself as a person?
0- Not at all
1
2- Slightly
3
4- Moderately

5
6- Markedly

206. How much would it upset you if you had to weigh yourself once a week for the next four weeks?
0- Not at all
1
2- Slightly
3
4- Moderately
5
6- Markedly

207. How dissatisfied have you felt about your weight?
0- Not at all
1
2- Slightly
3
4- Moderately
5
6- Markedly

208. How dissatisfied have you felt about your shape?
0- Not at all
1
2- Slightly
3
4- Moderately
5
6- Markedly

209. How concerned have you been about other people seeing you eat?
0- Not at all
1
2- Slightly
3
4- Moderately
5
6- Markedly

210. How uncomfortable have you felt seeing your body; for example, in the mirror, in shop window reflections, while undressing, or taking a bath or shower?
0- Not at all
1
2- Slightly
3

4- Moderately
5
6- Markedly

211. How uncomfortable have you felt about others seeing your body; for example, in communal changing rooms, when swimming, or wearing tight clothes?
0- Not at all
1
2- Slightly
3
4- Moderately
5
6- Markedly

Eating Attitudes Test (EAT-26: Garner, Olmsted, Bohr, & Garfinkel, 1982)

EAT-26
Please select a response for each of the following statements (Do not include weight changes due to pregnancy or physical illness):

64. Highest adult weight in pounds (lbs)

65. Lowest adult weight in pounds (lbs)

66. Am terrified about being overweight.
Always Usually Often Sometimes Rarely Never

67. Avoid eating when I am hungry.
Always Usually Often Sometimes Rarely Never

68. Find myself preoccupied with food.
Always Usually Often Sometimes Rarely Never

69. Have gone on eating binges where I feel I may not be able to stop.
Always Usually Often Sometimes Rarely Never

70. Cut my food into small pieces.
Always Usually Often Sometimes Rarely Never

71. Aware of the calorie content of foods I eat.
Always Usually Often Sometimes Rarely Never

72. Particularly avoid food with a high carbohydrate content (bread, rice, potatoes, etc.)
Always Usually Often Sometimes Rarely Never

73. Feel that others would prefer if I ate more.
Always Usually Often Sometimes Rarely Never

74. Vomit after I have eaten.
Always Usually Often Sometimes Rarely Never

75. Feel extremely guilty after eating.
Always Usually Often Sometimes Rarely Never

76. Am preoccupied with a desire to be thinner.
Always Usually Often Sometimes Rarely Never

77. Think about burning up calories when I exercise.

Always Usually Often Sometimes Rarely Never

78. Other people think I'm too thin.
Always Usually Often Sometimes Rarely Never

79. Am preoccupied with the thought of having fat on my body.
Always Usually Often Sometimes Rarely Never

80. Take longer than others to eat my meals.
Always Usually Often Sometimes Rarely Never

81. Avoid foods with sugar in them.
Always Usually Often Sometimes Rarely Never

82. Eat diet foods.
Always Usually Often Sometimes Rarely Never

83. Feel that food controls my life.
Always Usually Often Sometimes Rarely Never

84. Display self-control around food.
Always Usually Often Sometimes Rarely Never

85. Feel that others pressure me to eat.
Always Usually Often Sometimes Rarely Never

86. Give too much time and thought to food.
Always Usually Often Sometimes Rarely Never

87. Feel uncomfortable after eating sweets.
Always Usually Often Sometimes Rarely Never

88. Engage in dieting behaviour.
Always Usually Often Sometimes Rarely Never

89. Like my stomach to be empty.
Always Usually Often Sometimes Rarely Never

90. Have the impulse to vomit after meals.
Always Usually Often Sometimes Rarely Never

91. Enjoy trying new rich foods.
Always Usually Often Sometimes Rarely Never

92. Any additional comments?

Gormally Binge Eating Scale (GBES: Gnormally, Black, Daston, & Rardin, 1982)

GBES
Below are groups of numbered statements. Read all of the statements in each group and select the one that best describes the way you feel about the problems you have controlling your eating behavior.

53. 1.

I don't feel self-conscious about my weight or body size when I'm with others.

I feel concerned about how I look to others, but it normally does not make me feel disappointed with myself.

I do get self-conscious about my appearance and weight which makes me feel disappointed in myself.

I feel very self-conscious about my weight and frequently, I feel intense shame and disgust for myself. I try to avoid social contacts because of my self-consciousness.

54. 2.

I don't have any difficulty eating slowly in the proper manner.

Although I seem to "gobble down" foods, I don't end up feeling stuffed because of eating too much.

At times, I tend to eat quickly, and then, I feel uncomfortably full afterwards.

I have the habit of bolting down my food, without really chewing it. When this happens I usually feel uncomfortably stuffed because I've eaten too much.

55. 3.

I feel capable to control my eating urges when I want to.

I feel like I have failed to control my eating more than the average person.

I feel utterly helpless when it comes to feeling in control of my eating urges.

Because I feel so helpless about controlling my eating I have become very desperate about trying to get in control.

56. 4.

I don't have the habit of eating when I'm bored.

I sometimes eat when I'm bored, but often I'm able to "get busy" and get my mind off food.

I have a regular habit of eating when I'm bored, but occasionally, I can use some other activity to get my mind off eating.

I have a strong habit of eating when I'm bored. Nothing seems to help me break the habit.

57. 5.

I'm usually physically hungry when I eat something.

Occasionally, I eat something on impulse even though I really am not hungry.

I have the regular habit of eating foods that I might not really enjoy, to satisfy a hungry feeling even though physically, I don't need the food.

Even though I'm not physically hungry, I get a hungry feeling in my mouth that only seems to be satisfied when I eat a food, like a sandwich, that fills my mouth. Sometimes, when I eat the food to satisfy my mouth hunger, I then spit the food out so I won't gain weight.

58. 6.

I don't feel any guilt or self-hate after I overeat.

After I overeat, occasionally I feel guilt or self-hate.

Almost all the time I experience strong guilt or self-hate after I overeat.

59. 7.

I don't lose total control of my eating when dieting even after periods when I overeat.

Sometimes when I eat a "forbidden food" on a diet, I feel like I "blew it" and eat even more.

Frequently, I have the habit of saying to myself, "I've blown it now, why not go all the way" when I overeat on a diet. When that happens I eat even more.

I have a regular habit of starting strict diets for myself, but I break the diets by going on an eating binge. My life seems to be either a "feast" or "famine."

60. 8.

I rarely eat so much food that I feel uncomfortably stuffed afterwards.

Usually, about once a month, I eat such a quantity of food I end up feeling very stuffed.

I have regular periods during the month when I eat large amounts of food, either at mealtime or at snacks.

I eat so much food that I regularly feel quite uncomfortable after eating and sometimes a bit nauseous.

61. 9.

My level of calorie intake does not go up very high or go down very low on a regular basis.

Sometimes after I overeat, I will try to reduce my caloric intake to almost nothing to compensate for the excess calories I've eaten.

I have a regular habit of overeating during the night. It seems that my routine is not to be hungry in the morning but overeat in the evening.

In my adult years, I have had week-long periods where I practically starve myself. This follows periods when I overeat. It seems I live a life of either "feast or famine."

62. 10.

I usually am able to stop eating when I want to. I know when "enough is enough."

Every so often, I experience a compulsion to eat which I can't seem to control.

Frequently, I experience strong urges to eat which I seem unable to control, but at other times I can control my eating urges.

I feel incapable of controlling urges to eat. I have a fear of not being able to stop eating voluntarily.

63. 11.

I don't have any problem stopping eating when I feel full.

I usually can stop eating when I feel full but occasionally overeat leaving me feeling uncomfortably stuffed.

I have a problem stopping eating once I start and usually I feel uncomfortably stuffed after I eat a meal.

Because I have a problem not being able to stop eating when I want, I sometimes have to induce vomiting to relieve my stuffed feeling.

64. 12.

I seem to eat just as much when I'm with others (family, social gatherings) as when I'm by myself.

Sometimes, when I'm with other persons, I don't eat as much as I want to eat because I'm self-conscious about my eating.

Frequently, I eat only a small amount of food when others are present, because I'm very embarrassed about my eating.

I feel so ashamed about overeating that I pick times to overeat when I know no one will see me. I feel like a "closet eater."

65. 13.

I eat three meals a day with only an occasional between meal snack.

I eat 3 meals a day, but I also normally snack between meals.

When I am snacking heavily, I get in the habit of skipping regular meals.

There are regular periods when I seem to be continually eating, with no planned meals.

66. 14.

I don't think much about trying to control unwanted eating urges.

At least some of the time, I feel my thoughts are pre-occupied with trying to control my eating urges.

I feel that frequently I spend much time thinking about how much I ate or about trying not to eat anymore.

It seems to me that most of my waking hours are pre-occupied by thoughts about eating or not eating. I feel like I'm constantly struggling not to eat.

67. 15.

I don't think about food a great deal.

I have strong cravings for food but they last only for brief periods of time.

I have days when I can't seem to think about anything else but food.

Most of my days seem to be pre-occupied with thoughts about food. I feel like I live to eat.

68. 16.

I usually know whether or not I'm physically hungry. I take the right portion of food to satisfy me.

Occasionally, I feel uncertain about knowing whether or not I'm physically hungry. At these times it's hard to know how much food I should take to satisfy me.

Even though I might know how many calories I should eat, I don't have any idea what is a "normal" amount of food for me.

Beck Depression Inventory-II (BDI-II: Beck, Steer, & Brown, 1996)

BDI-II
This questionnaire consists of 21 groups of statements. Please read each group of statements carefully, and then pick out the ONE STATEMENT in each group that best describes the way you have been feeling during the PAST 2 WEEKS, INCLUDING TODAY. If several statements in the group seem to apply equally well, choose the highest number for that group. Be sure that you do not choose more than one statement for any group.

186. Sadness
0- I do not feel sad
1- I feel sad much of the time
2- I am sad all the time
3- I am so sad or unhappy that I can't stand it

187. Pessimism
0- I am not discouraged about my future
1- I feel more discouraged about my future that I used to be
2- I do not expect things to work out for me
3- I feel my future is hopeless and will only get worse

188. Past Failure
0- I do not feel like a failure
1- I have failed more than I should have
2- As I look back, I see a lot of failures
3- I feel I am a total failure as a person

189. Loss of Pleasure
0- I get as much pleasure as I ever did from the things I enjoy
1- I don't enjoy things as much as I used to
2- I get very little pleasure from the things I used to enjoy
3- I can't get any pleasure from the things I used to enjoy

190. Guilty Feelings
0- I don't feel particularly guilty
1- I feel guilty over many things I have done or should have done
2- I feel quite guilty most of the time
3- I feel guilty all of the time

191. Punishment Feelings
0- I don't feel I am being punished
1- I feel I may be punished
2- I expect to be punished
3- I feel I am being punished

192. Self-Dislike
0- I feel the same about myself as ever
1- I have lost confidence in myself
2- I am disappointed in myself
3- I dislike myself

193. Self-Criticalness
0- I don't criticize or blame myself more than usual
1- I am more critical of myself than I used to be
2- I criticize myself for all of my faults
3- I blame myself for everything bad that happens

194. Suicidal Thoughts or Wishes
0- I don't have any thoughts of killing myself
1- I have thoughts of killing myself, but I would not carry them out
2- I would like to kill myself
3- I would kill myself if I had the chance

195. Crying
0- I don't cry anymore than I used to
1- I cry more than I used to
2- I cry over every little thing
3- I feel like crying, but I can't

196. Agitation
0- I am no more restless or wound up than usual
1- I feel more restless or wound up than usual
2- I am so restless or agitated that it's hard to stay still
3- I am so restless or agitated that I have to keep moving or doing something

197. Loss of Interest
0- I have not lost interest in other people or activities
1- I am less interested in other people or things than before
2- I have lost most of my interest in other people or things
3- It's hard to get interested in anything

198. Indecisiveness
0- I make decisions about as well as ever
1- I find it more difficult to make decisions than usual
2- I have much greater difficulty in making decisions than I used to
3- I have trouble making any decisions

199. Worthlessness
0- I do not feel I am worthless
1- I don't consider myself as worthwhile and useful as I used to
2- I feel more worthless as compared to other people

3- I feel utterly worthless

200. Loss of Energy
0- I have as much energy as ever
1- I have less energy than I used to have
2- I don't have enough energy to do very much
3- I don't have enough energy to do anything

201. Changes in Sleeping Pattern
0- I have not experienced any change in my sleeping pattern
1a- I sleep somewhat more than usual
1b- I sleep somewhat less than usual
2a- I sleep a lot more than usual
2b- I sleep a lot less than usual
3a- I sleep most of the day
3b- I wake up 1-2 hours early and can't get back to sleep

202. Irritability
0- I am no more irritable than usual
1- I am more irritable than usual
2- I am much more irritable than usual
3- I am irritable all the time

203. Changes in Appetite
0- I have not experienced any change in my appetite
1a- My appetite is somewhat less than usual
1b- My appetite is somewhat greater than usual
2a- My appetite is much less than before
2b- My appetite is much greater than usual
3a- I have no appetite at all
3b- I crave food all the time

204. Concentration Difficulty
0- I can concentrate as well as ever
1- I can't concentrate as well as usual
2- It's hard to keep my mind on anything for very long
3- I find I can't concentrate on anything

205. Tiredness or Fatigue
0- I am no more tired or fatigued than usual
1- I get more tired or fatigued more easily than usual
2- I am too tired or fatigued to do a lot of the things I used to do
3- I am too tired or fatigued to do most of the things I used to do

206. Loss of Interest in Sex
0- I have not noticed any recent change in my interest in sex

1- I am less interested in sex than I used to be
2- I am much less interested in sex now
3- I have lost interest in sex completely

207. Any additional comments?

Beck Anxiety Inventory (BAI: Beck & Steer, 1993a)

BAI
Below is a list of common symptoms of anxiety. Please carefully read each item in the list. Indicate how much you have been bothered by that symptom during the past month, including today, by selecting the appropriate response.

208. Numbness or tingling
Not at all.
Mildly, but it didn't bother me much.
Moderately - it wasn't pleasant at times.
Severely - it bothered me a lot.

209. Feeling hot
Not at all.
Mildly, but it didn't bother me much.
Moderately - it wasn't pleasant at times.
Severely - it bothered me a lot.

210. Wobbliness in legs
Not at all.
Mildly, but it didn't bother me much.
Moderately - it wasn't pleasant at times.
Severely - it bothered me a lot.

211. Unable to relax
Not at all.
Mildly, but it didn't bother me much.
Moderately - it wasn't pleasant at times.
Severely - it bothered me a lot.

212. Fear of the worst happening
Not at all.
Mildly, but it didn't bother me much.
Moderately - it wasn't pleasant at times.
Severely - it bothered me a lot.

213. Dizzy or lightheaded
Not at all.
Mildly, but it didn't bother me much.
Moderately - it wasn't pleasant at times.
Severely - it bothered me a lot.

214. Heart pounding/racing
Not at all.
Mildly, but it didn't bother me much.

Moderately - it wasn't pleasant at times.
Severely - it bothered me a lot.

215. Unsteady
Not at all.
Mildly, but it didn't bother me much.
Moderately - it wasn't pleasant at times.
Severely - it bothered me a lot.

216. Terrified or afraid
Not at all.
Mildly, but it didn't bother me much.
Moderately - it wasn't pleasant at times.
Severely - it bothered me a lot.

217. Nervous
Not at all.
Mildly, but it didn't bother me much.
Moderately - it wasn't pleasant at times.
Severely - it bothered me a lot.

218. Feeling of choking
Not at all.
Mildly, but it didn't bother me much.
Moderately - it wasn't pleasant at times.
Severely - it bothered me a lot.

219. Hands trembling
Not at all.
Mildly, but it didn't bother me much.
Moderately - it wasn't pleasant at times.
Severely - it bothered me a lot.

220. Shaky/unsteady
Not at all.
Mildly, but it didn't bother me much.
Moderately - it wasn't pleasant at times.
Severely - it bothered me a lot.

221. Fear of losing control
Not at all.
Mildly, but it didn't bother me much.
Moderately - it wasn't pleasant at times.
Severely - it bothered me a lot.

222. Scared

Not at all.
Mildly, but it didn't bother me much.
Moderately - it wasn't pleasant at times.
Severely - it bothered me a lot.

223. Indigestion
Not at all.
Mildly, but it didn't bother me much.
Moderately - it wasn't pleasant at times.
Severely - it bothered me a lot.

224. Faint
Not at all.
Mildly, but it didn't bother me much.
Moderately - it wasn't pleasant at times.
Severely - it bothered me a lot.

225. Face flushed
Not at all.
Mildly, but it didn't bother me much.
Moderately - it wasn't pleasant at times.
Severely - it bothered me a lot.

226. Hot/cold sweats
Not at all.
Mildly, but it didn't bother me much.
Moderately - it wasn't pleasant at times.
Severely - it bothered me a lot.

227. Any additional comments?

Rosenberg Self-Esteem Scale (RSES: Rosenberg, 1965)

Self-Esteem Scale

Below is a list of statements dealing with your general feelings about yourself. Please choose the selection that best fits how you feel about each statement.

137. On the whole, I am satisfied with myself.
Strongly agree
Agree
Disagree
Strongly disagree

138. At times I think I am no good at all.
Strongly agree
Agree
Disagree
Strongly disagree

139. I feel that I have a number of good qualities.
Strongly agree
Agree
Disagree
Strongly disagree

140. I am able to do things as well as most other people.
Strongly agree
Agree
Disagree
Strongly disagree

141. I feel I do not have much to be proud of.
Strongly agree
Agree
Disagree
Strongly disagree

142. I certainly feel useless at times.
Strongly agree
Agree
Disagree
Strongly disagree

143. I feel that I'm a person of worth, at least on an equal plane with others.
Strongly agree
Agree

Disagree
Strongly disagree

144. I wish I could have more respect for myself.
Strongly agree
Agree
Disagree
Strongly disagree

145. All in all, I am inclined to feel that I am a failure.
Strongly agree
Agree
Disagree
Strongly disagree

146. I take a positive attitude toward myself.
Strongly agree
Agree
Disagree
Strongly disagree

The Body Esteem Scale (BES: Franzoi & Shields, 1984)

BES
On this page are a number of body parts and functions. Please read each item and indicate how you feel about this part or function of your own body using the scale indicated.

150. Body scent
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

151. Appetite
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

152. Nose
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

153. Physical stamina
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

154. Reflexes
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

155. Lips
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings

Have strong positive feelings

156. Muscular strength
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

157. Waist
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

158. Energy level
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

159. Thighs
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

160. Ears
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

161. Biceps
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

162. Chin
Have strong negative feelings

Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

163. Body build
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

164. Physical coordination
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

165. Buttocks
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

166. Agility
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

167. Width of shoulders
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

168. Arms
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

169. Chest or breasts
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

170. Appearance of eyes
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

171. Cheeks/cheekbones
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

172. Hips
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

173. Legs
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

174. Figure or physique
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

175. Sex drive
Have strong negative feelings
Have moderate negative feelings

Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

176. Feet
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

177. Sex organs
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

178. Appearance of stomach
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

179. Health
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

180. Sex activities
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

181. Body hair
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

182. Physical condition
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

183. Face
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

184. Weight
Have strong negative feelings
Have moderate negative feelings
Have no feeling one way or the other
Have moderate positive feelings
Have strong positive feelings

185. Any additional comments?

The Appearance Schemas Inventory- Revised (ASI-R: Cash, Melnyck, & Hrabosky, 2004)

ASI
The statements below are beliefs that people may or may not have about their physical appearance and its influence on life. Decide on the extent to which you personally disagree or agree with each statement. There are no right or wrong answers. Just be truthful about your personal beliefs.

212. I spend little time on my physical appearance.
Strongly Disagree
Mostly Disagree
Neither Agree or Disagree
Mostly Agree
Strongly Agree

213. When I see good-looking people, I wonder about how my own looks measure up.
Strongly Disagree
Mostly Disagree
Neither Agree or Disagree
Mostly Agree
Strongly Agree

214. I try to be as physically attractive as I can.
Strongly Disagree
Mostly Disagree
Neither Agree or Disagree
Mostly Agree
Strongly Agree

215. I have never paid much attention to what I look like.
Strongly Disagree
Mostly Disagree
Neither Agree or Disagree
Mostly Agree
Strongly Agree

216. I seldom compare my appearance to that of other people I see.
Strongly Disagree
Mostly Disagree
Neither Agree or Disagree
Mostly Agree
Strongly Agree

217. I often check my appearance in a mirror just to make sure I look okay.
Strongly Disagree

Mostly Disagree
Neither Agree or Disagree
Mostly Agree
Strongly Agree

218. When something makes me feel good or bad about my looks, I tend to dwell on it.
Strongly Disagree
Mostly Disagree
Neither Agree or Disagree
Mostly Agree
Strongly Agree

219. If I like how I look on a given day, it's easy to feel happy about other things.
Strongly Disagree
Mostly Disagree
Neither Agree or Disagree
Mostly Agree
Strongly Agree

220. If somebody had a negative reaction to what I look like, it wouldn't bother me.
Strongly Disagree
Mostly Disagree
Neither Agree or Disagree
Mostly Agree
Strongly Agree

221. When it comes to my physical appearance, I have high standards.
Strongly Disagree
Mostly Disagree
Neither Agree or Disagree
Mostly Agree
Strongly Agree

222. My physical appearance has little influence on my life.
Strongly Disagree
Mostly Disagree
Neither Agree or Disagree
Mostly Agree
Strongly Agree

223. Dressing well is not a priority for me.
Strongly Disagree
Mostly Disagree
Neither Agree or Disagree
Mostly Agree
Strongly Agree

224. When I meet people for the first time, I wonder what they think about how I look.
Strongly Disagree
Mostly Disagree
Neither Agree or Disagree
Mostly Agree
Strongly Agree

225. In my everyday life, lots of things happen that make me think about what I look like.
Strongly Disagree
Mostly Disagree
Neither Agree or Disagree
Mostly Agree
Strongly Agree

226. If I dislike how I look on a given day, its hard to feel happy about other things.
Strongly Disagree
Mostly Disagree
Neither Agree or Disagree
Mostly Agree
Strongly Agree

227. I fantasize about what it would be like to be better looking than I am.
Strongly Disagree
Mostly Disagree
Neither Agree or Disagree
Mostly Agree
Strongly Agree

228. Before going out, I make sure I look as good as I possibly can.
Strongly Disagree
Mostly Disagree
Neither Agree or Disagree
Mostly Agree
Strongly Agree

229. What I look like is an important part of who I am.
Strongly Disagree
Mostly Disagree
Neither Agree or Disagree
Mostly Agree
Strongly Agree

230. By controlling my appearance, I can control many of the social and emotional events in my life.
Strongly Disagree

Mostly Disagree
Neither Agree or Disagree
Mostly Agree
Strongly Agree

231. My appearance is responsible for much of what's happened to me in my life.
Strongly Disagree
Mostly Disagree
Neither Agree or Disagree
Mostly Agree
Strongly Agree

232. Any additional comments?

The Physical Disability and Sexual-Esteem Scale (PDSES: Taleporos & McCabe, 2002)

PDSBE
Please indicate your response to the following statements by selecting the appropriate answer corresponding to the degree to which you agree or disagree with each statement. Your responses should reflect your personal opinions and feelings about your disability, your body and your sexuality.

254. I feel that my disability interferes with my sexual enjoyment.
Strongly Agree
Agree
Don't Know
Disagree
Strongly Disagree

255. It is harder to find a sexual partner when you have a disability.
Strongly Agree
Agree
Don't Know
Disagree
Strongly Disagree

256. I would like to hide my disability as much as possible.
Strongly Agree
Agree
Don't Know
Disagree
Strongly Disagree

257. I feel sexually frustrated because of my disability.
Strongly Agree
Agree
Don't Know
Disagree
Strongly Disagree

258. I feel that my disability is likely to prevent me from satisfying a sexual partner.
Strongly Agree
Agree
Don't Know
Disagree
Strongly Disagree

259. My sexual expression is limited by my disability.
Strongly Agree

Agree
Don't Know
Disagree
Strongly Disagree

260. I feel that people are not sexually interested in me because of my disability.
Strongly Agree
Agree
Don't Know
Disagree
Strongly Disagree

261. I envy people with 'normal' bodies.
Strongly Agree
Agree
Don't Know
Disagree
Strongly Disagree

262. I believe that I experience rejection from potential sexual partners because of my disability.
Strongly Agree
Agree
Don't Know
Disagree
Strongly Disagree

263. I would do a body swap with an able-bodied person if I could.
Strongly Agree
Agree
Don't Know
Disagree
Strongly Disagree

264. Any additional comments?

Appendix D

List of Sample Interview Questions for Study 2

1. Can you describe your disability and how it impacts your life? Physically? Socially? Emotionally? Occupationally? Other?

2. Can you describe how much you need to depend on others because of your disability?

3. How has your eating been these days?

4. Can you say something about how your physical disability relates to your eating?

5. Can you say something about how your disability relates to how you feel about your body?

6. Can you share your personal history of eating concerns/body image concerns?

7. Have you had any experience trying to get support for your problematic eating?

8. Is maintaining a healthy lifestyle important to you?

9. What does healthy lifestyle mean to you?

10. How do you maintain balance or a healthy lifestyle?

11. What barriers have you experiences in attempting to maintain a healthy lifestyle?

12. Do you exercise? Can you tell me about that?

13. Additional themes to follow up on:
    a. Attendant care services
    b. Puberty
    c. Protective factors
    d. Compensating for disability with diet and/or appearance
    e. Weight-loss for the benefit of others
    f. Restricting fluids
    g. Stress responses
    h. Body autonomy/medical gaze
    i. Seeking support
    j. Weight loss attempts? Doctor recommended?
    k. Blame self for medical problems

Appendix E

Initial Codes

Codes –May 6, 2014

1) Wishing to not be disabled
2) Why me? Life is unfair
3) What Adaptive means
4) Weight Estimation of Disability
5) Web of Symptoms
6) Wanting to be sexually objectified
7) Violent rejection of food
8) Unobtainable goal of the ideal body
9) Unhealthy weight
10) Unfilled hole of acceptance
11) Undesirable obesity
12) Trespassing
13) Trauma
14) Trapped between 2 cultures
15) Tolerated by others but not accepted
16) Time to ruminate
17) Thin helps me pass as normal
18) There is something wrong with my body
19) The unwanted due to ability
20) The unwanted body
21) The lesser of 2 evils
22) Ten turmoil
23) System of control
24) Superchip
25) Super coper
26) Strong self-critic
27) Strict planning
28) Stress of chronic pain
29) Stress eating
30) Social savior
31) Social function of weight and appearance
32) Slave to food
33) Sexualization as resistance
34) Sexual comparison
35) Settle
36) Self-worth dependent on weight
37) Self-hate
38) Self-awareness distress
39) Seeking acceptance of the other
40) Sedentary lifestyle
41) Search for the perfect body
42) Scrutinized and dissected

43) Scheduled chaos
44) Sacrificing m life for others
45) Sacrificing health
46) Routine
47) Restriction my secret weapon
48) Restricting fluid
49) Resorting to weight loss
50) Resisting treatment
51) Resistance to the norm
52) Resistance to stereotype
53) Resistance to forced restriction
54) Resistance to assumptions
55) Resilience
56) Resentment of the fact that I can't eat
57) Rejection
58) Regrets from eating poorly
59) Reframing as a gift
60) Reframing as a cultural or social issue
61) Reduced to less than human
62) Rebellious teenager
63) Readjusting to body image
64) Reaction to puberty and body changes
65) Prove your worth
66) Protective factors of disability on eating
67) Protecting oneself
68) Praise for thinness
69) Powerlessness
70) Physical needs override emotional
71) Personal autonomy to food
72) Permission to acknowledge other problems beside disability
73) Peer relations
74) Passing as normal
75) Overexercise
76) Outlier
77) Othering
78) Optimism
79) Ongoing eating struggle
80) Obesity is disabling
81) Nutritional purgatory
82) Not wanting to complain
83) Normalized struggle
84) Non-medicalized touch
85) No one can support me
86) Needing to be fixed
87) My past thinner healthy self
88) Motivated by the other

89) Mobility is everything
90) Misunderstanding
91) Misdiagnosis
92) Minimizing or dismissing
93) Minimize hurtful comments
94) Mental health issue
95) Media impact
96) Maintaining some control
97) Long hanging fruit
98) Losing control of eating
99) Long medical road
100) Locus of control
101) Limited freedom
102) Limited energy to spend
103) Life is hard, give me this
104) Left out
105) Lebel bug
106) Lack of agency
107) Judgment of others
108) Journey of acceptance
109) Jesus take the wheel
110) It's for your own good
111) Isolation
112) Invisible
113) Invasion of privacy
114) Intimate relationships
115) Internalizing messages disability less than
116) Interesting quote gender
117) Inaccessible treatment
118) Importance of representation and role models
119) Importance of psychotherapy support
120) Importance of peer support
121) Importance of beauty
122) Importance of accessible exercise
123) I need too much
124) I am my own doctor
125) Hierarchy of comparison
126) Hiding disability in public
127) Helplessness hate depending on others
128) Healthy consequences magnified and it's hard
129) Guilt from the other
130) Frustration to barriers
131) Forced social locations
132) Forced segregation sports
133) Forced into identity
134) Food like a drug

135) Food consolation prize
136) Food as an emotional soother
137) Food as a source of shame
138) Food and calorie counting as distraction
139) Focus on beauty I can change
140) Fitness family
141) Finding meaning in disability struggle
142) Finding inner advocate
143) Finding agency
144) Finding a community
145) Finding a balance
146) Financial barriers
147) Feeling supported
148) Feeling special
149) Feeling productive
150) Feeling like the other reminded of differences
151) Feeling inadequate of not good enough
152) Feeling hopeless or giving up
153) Fear of HCP judging weight
154) Fat language
155) Family pass of eating habits
156) Family concern about weight
157) Family ashamed of disability
158) Extra baggage
159) Exercise is empowering
160) Even the binges are planned
161) Escaping from reality
162) End of interview comments
163) Empowered by weight loss
164) Eating as bonding
165) Early feeding issues
166) Double whammy
167) Distancing from disability
168) Disfigured
169) Disempowered to exercise
170) Disempowered medically
171) Discounting disability from beauty race
172) Discomfort with concern from others
173) Disability makes me look larger
174) Disability lifestyle reinforces ED
175) Disability does not define me
176) Disability discussion in therapy
177) Disability description
178) Disability denial
179) Disability as an excuse
180) Different of first of that kind

181) Difficulty with change
182) Difficulty finding a balance in eating
183) Diet description
184) Description of help needed
185) Defines problem with other people
186) Cured at gunpoint
187) Cultural messages of desirability
188) Critical of own eating
189) Critical of disability
190) Crashing down
191) Costly cosmetic normalcy
192) Controlling appearance
193) Constant uphill battle
194) Constant surveillance
195) Constant self-vigilance
196) Conflict gratitude vs. despair
197) Conflict disability and eating
198) Conflict advocacy vs. fitting in
199) Complex cases
200) Complete lack of faith in medical
201) Compensatory behaviours
202) Compensation
203) Comparing appearance to norm
204) Coming out as disabled
205) Clothing that doesn't fit my body
206) Choosing your identity
207) Choosing to lose agency
208) Catharsis
209) But you don't understand
210) Body nitpicking
211) Blinders
212) Beyond my specialty area
213) Being on display
214) Being forced into identity
215) Barbie in wheelchairs
216) Attracting a mate
217) Attendant control
218) Attendant comments on weight
219) Ashamed of disability
220) Are you training for the Olympics
221) Allure of the magic cure
222) Admitting you need support
223) Admitting defeat
224) Accessing life
225) Acceptance of disability
226) Acceptance in therapy

Initial Coding Tree

Disability Description
- Diagnosis Type (Medical)
- Congenital vs. Acquired
- Invisible vs. Visible

Impact of Disability
- Physically
- Functionally
    - How much Assistance require (Attendant care)
    - Energy Levels
    - Pain Levels
- Emotionally
- Socially
    - Lack of Transportation
    - Inaccessible social locations
- Normalized Struggle
- Acceptance vs. Resentment

Disability impacts Eating
Eating impacts Disability (weight gain)
- Mobility
- Chronic Pain
- Attitude

Food
- Food to sooth stress/emotions
- Food as social bonding (Accessible activity)
- Food as compensation (after difficult appointment)
- Food as an addiction
- Food as a reward
- Food as Shame/Guilt
- Food as a distraction (counting calories)

Disordered Eating Issues Unique to WWDs
- "Nutritional Purgatory"
- Avoiding Eating (Public) due to shame around physical differences (hand deformities, stares, lack of fine motor skills)
- Difficulty estimating weight
    - BMI recommendations
    - Scales not accessible
    - Using seatbelts/wheelchair size.
- Lack of Mobility
    - Weight gain creates greater disability
    - Caloric Restriction my only option

    - Confusion over health risks of exercising
    - Costly or inaccessible gyms
- Constant Self-vigilance
- Weight gain = End of Independence - "Cured at Gunpoint"
- Dependency
    - See below
- Disability Makes me Look Larger
    - Targeted weight gain (SMA pooch)
    - Swelling
    - Scoliosis
- Stress Eating
    - Stress of navigating inaccessible locations
    - Stress of transportation
    - Stress of dealing in persons who were not accommodating/judgmental
    - Food associated with reward/pleasure
- One more thing…
- Extra Pressure to look good
    - Avoid stereotype of PWD
- Restricting Fluids
- Avoid stigma of being fat
    - "The Fat Disabled Girl" – not wanting to make life harder
    - Blamed for disability
    - Fear of being physically unattractive/monstrosity

Seeking Support

- Physically Inaccessible locations
- Financial Barriers
- Feeling "on your own"
    - Self-expert
    - Develop own dieting and exercise recommendations after perceived confusion on behalf of HCP.
    - Why bother?
- Medical Trauma
    - Lack of autonomy/privacy over own body
    - Past experiences prevent access
    - Treated like patient (diagnosis) vs. person
    - Stereotyped (asexual, uninformed)
    - Language (deformed)
- Fear
    - Losing weight as life or death
- Feeling Misunderstood or Complicated
    - Always feeling "First of that kind"
- Too difficult
    - Not understanding accommodations needed
    - Excluded by rules of program
- Feeling like the "Other"

    - Only WWD
    - Being weighed – "Circus sideshow"
    - Stares for needing assistance (writing, eating, washroom, etc.)
    - The Medical Gaze - Treated like a diagnoses
- Not Necessary
- Another task in the overwhelming pile
- Disability Overshadows all other problems
    - ED is missed
    - Mental health is dismissed
    - Weight loss and maintaining independence prioritized

Protective Factors of the Disability

- Not being able to over-exercise
- Acceptance of disability came with acceptance that she will never look like women in magazines
- Not being able to purge
- Not being able to binge eat
- Maintaining medical stability (electrolyte balance)

Body Image

- Social Comparison
    - Body Comparison to AB women
    - Feeling like never measure up to an ideal image
    - Letting go of that goal to measure up
    - Comparing self to other WWD (Barbies in Wheelchairs)
- Readjusting body image standards connected to acceptance of disability
- Internalized societal view of disability as a problem
    - No one chooses this life
- Undesirable Fat
    - Unhealthy
    - Inhibits mobility
    - Indicates a lack of control/care
    - Unattractive
- Lack of Representation of WWD
    - Compare to idealized media images
    - Feeling of being invisible

Onset of Eating Problems

- Puberty
- Transition/Changes
    - Moving schools
    - Losing friends
    - Moving country
- Attraction to Opposite sex
    - First rejection
- Accident or Trauma

- Major Health Diagnosis
- Comments/Encouragement from Family Members
- Peers

Control

- Breaking from the trap
    - Finding body autonomy (purging, dieting, bingeing)
    - Spontaneous (of eating out)
- Empowerment
    - Controlling eating
    - Seeing results/becoming thin (pride)
- Focus on areas I can control
    - Can control tummy size, can't control swelling/disability
- Life is: "Scheduled Chaos"
    - Eating on a schedule
    - Attendants on a schedule (washroom)

Compensation

- Passing as normal
- Balance scale – make up for disability
- Overcompensating
- Impressing others
- Controlled attributes: beauty, clothing, intelligence, etc.

Dependency

- Attendants
- Parents
- Friends
- Partners
- Body Autonomy
- Ease caregiver burden
- Comments on weight
- Constant Surveillance

Journey of Acceptance

- Identify as 'Disabled'
    - What does disability mean to you?
- Social vs. Medical Model of Disability
- Struggle between accepting society's view of disability and accepting self
- Support from Disability Community
- View self as separate vs. apart of the disability community
- Finding self-worth in areas outside of ability/appearance
- Wishing to be AB vs. accepting self as disabled
- Openness about disability - coming out as disabled

Sexuality & Relationships

- Meaning/Importance of Relationships
    - Providing social power
    - Providing normalcy ("I've made it")
    - Validation of physical beauty
    - Comfort/confidence with body
    - Acceptance/Self-worth
    - Importance of non-medical touch
    - Validation of sexual being
    - Resistance to asexuality stereotype
    - Resistance to stereotype of disability being unattractive/child-like
- Low Hanging Fruit
    - Fear of settling
- Impact of Relationship on Eating
    - Fear of gaining weight (lifted by partner)
    - Maintain independence (not wanting to become a burden)

Peer Relations

- Support system or source of stress
- Social comparison
    - Sexual comparison
- Friends with disabilities.
- Teasing or exclusion

Family Relations

- Reactions to dieting
- Reactions to serious weight loss or purging
- Supportive vs. unsupportive
- Value of Physical Ability in Family
- Response to body changes
- Acceptance of disability & limitations (progressive)
- Family response to disability in public (shame)
- It's for your own good (health advice)
- Family controlling food intake
    - Resistance to forced restriction

Rejection of Social Ideals/Resilience

- Self-awareness of dieting culture
- Self-awareness of media's unrealistic beauty standards
- Stop social comparison
- Not caring what others think
- Acceptance through partners
- Finding support
- Telling your story (Same story as others)

Interview Experiences

- Important/providing a voice

- Less isolated
- Catharsis
- More self-awareness
- Difficult to share/recall these memories

Appendix F

Final Coding Tree

Core Category: Thriving And Surviving In A World That Is Not Designed For Disability And Difference

Core Category: THE EXPERIENCE OF DIFFERENCE

Functional Differences (1st Level Subcategory)

Disabled Bodies Cannot Be Healthy (2nd Level Subcategory)
Sedentary Lifestyle (3rd Level Subcategory)
Fit Is The Ideal (3rd)
Disability Trump Card (3rd)
The "Lemon" Body (3rd)

Doubly Disabling (2nd Level)
Constant Surveillance (3rd)
Attempting Cure At Gunpoint (3rd)

Constant Uphill Battle (2nd Level)
Prone To Weight Gain (3rd)
Nutritional Purgatory (3rd)

The Cost Of Support (2nd)
The Compromise (3rd)
Strict Routine (4th)
Lack Of Agency And Control (4th)

Complex Cases (3rd)
Blinders (4th)
Feeling Misunderstood Or "Special" (4th)

Disempowered (3rd)

Barriers To Healthy Living Support (3rd)

Embodiment Differences (1st Level Subcategory)

Body Esteem (2nd Level Subcategory)
Comparison To The Norm (3rd)
Body Nitpicking (3rd)

The Spoiled Fruit (2nd)

Media Messages (2nd)

Left Out (3rd)
Unobtainable Goal Of The Ideal Body (3rd)

Abnormal Bodies (2nd)

Social Differences (1st Level Subcategory)

Intolerance For Difference (2nd)

Problem Of Disability (3rd)
The "Fat Disabled Girl" (3rd)

Lack Of Acceptance And Inclusion (2nd)

Isolated And Invisible (3rd)
The Unexpected Guest (3rd)

Developmental Importance Of Puberty (2nd)

Highlighting Differences From Peers (3rd)
Bullying And Teasing (3rd)
Lacking Social Capital (3rd)

Hidden In Plain Sight (2nd)

Normalized Abuse (3rd)

Medical Trauma (3rd)
Circus Sideshow (4th)
Inaccessible Treatment (4th)

Appendix G

Full Hierarchical Model Study 2